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ABSTRACT

This guide is intended to help those providing services to infants and young children with special needs to work more effectively and collegially with family members at the program and policy level. The guide stresses the benefits and barriers to family participation in advisory activities and offers guidelines for promoting family participation. It also offers specific strategies for identifying families to serve in advisory capacities, approaches for supporting and maintaining their involvement, and ideas for expanding the networks of parents who provide input and guidance at the policy level. Included throughout are examples of family/professional collaboration that demonstrate the diversity of ways that families are influencing policy and practice in health and other human service organizations and institutions. The guide emphasizes approaches for involving families who, because of socioeconomic status, educational background, or language or cultural differences, have been under-represented in advisory roles. Appendices provide sample job descriptions, samples of materials for recruiting and selecting families for staff positions, and sample documents for developing family advisory boards. (Contains 23 references.) (DB)

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Essential Allies

FAMILIES AS ADVISORS

ELIZABETH S. JEPPSON

JOSIE THOMAS

INSTITUTE FOR FAMILY-CENTERED CARE
With support from the Maternal & Child Health Bureau
U.S. Department of Health & Human Services

EC 305 227

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The Institute for Family-Centered Care serves as a central resource for policy makers, program planners, direct care providers, educators of health professionals, architects and designers, and families on the implementation of family-centered care in local communities, at the state level, and nationally. Staff of the Institute develop written and audiovisual educational materials, disseminate information on best practices, and conduct policy and research initiatives. The Institute also offers on-site and off-site training, technical assistance, and consultation to state agencies, hospitals, community organizations, and medical education programs to help translate the concepts of family-centered care into practice.

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Introduction

I work collaboratively with families not only because it's the right way to do things, but because it's the most enjoyable, energizing, and satisfying way to provide services.

Wallace, in Bishop, Woll, & Arango, 1993

Throughout the country, families and professionals* are working together in new ways. They are collaborating in the development of individualized family service plans for infants and toddlers in early intervention programs; co-leading preservice and inservice training sessions for health care providers; and creating innovative programs to increase community support for families. In addition, they are participating jointly on committees and task forces to shape policies and programs to improve care and support for children and families. Overwhelmingly families and providers express excitement about these new collegial relationships and describe the positive changes that can, and have, occurred when parents and professionals work together (Bailey, Buysse, Smith, & Elam, 1992). Families are realizing the impact and influence they can have in shaping policies and programs. Providers are recognizing that consumer involvement is integral to designing a service system that is both responsive and cost effective.

While there is growing consensus that a collaborative approach humanizes the service delivery system, improves outcomes for children, and results in greater satisfaction for both providers and families, the partnership paradigm is radically different from the client/provider relationship in which most professionals were schooled. Providers, for the most part, have not had opportunities to learn to work with families in these new ways. For families as well, the development of effective, collegial relationships with professionals requires new attitudes and skills.

This publication was developed to help bridge the gap between providers' past training and experience and these new expectations of collaboration and partnership with families. The information and tools provided in *Essential Allies: Families as Advisors* equip providers to work more effectively and collegially with family members at the program and policy level. A companion document for families presents information and resources on serving in advisory roles.

Essential Allies is intended to be very practical. The benefits and barriers to family participation in advisory activities are briefly reviewed in the opening sections. The remainder of the publication presents guidelines for promoting

*Throughout this book, "families" refers to parents, foster parents, or extended family members who serve a caregiving role in a child's life. "Professionals" are health or other human service personnel who provide services to children and families. The authors recognize that many family members also hold professional positions, but have selected these words because of their common usage in the field.

family participation and offers specific strategies for identifying families to serve in advisory capacities, approaches for supporting and maintaining their involvement, and ideas for expanding the networks of parents who provide input and guidance at the policy level. Included throughout are examples of family/professional collaboration that demonstrate the diversity of ways that families are influencing policy and practice in health and other human service organizations and institutions across the country. *Essential Allies* emphasizes approaches for involving families who, because of socioeconomic status, educational background, or language or cultural differences, have been underrepresented in advisory roles.

Essential Allies: Families as Advisors is written for those who are excited about and committed to forging new relationships with families. It is not intended to "sell" the idea of collaboration. Instead, it draws upon the rich experience and insights of providers and families engaged in creative, collaborative relationships to provide inspiration, guidance, and support for moving forward with this essential work.

Advisors and Consultants: Roles Families Play

The range of advisory roles that families can play is almost limitless. Although many people think of a formal task force or committee when discussing the advisory functions that families perform, the concept can, and should, be more broadly conceived. The term "advisory" should be used to describe any role that enables family members to have direct input and influence on policies, programs, and practices that impact on the care and services children and families receive. Presented below are some of the advisory roles and functions that families can perform.

ADVISORY ROLES FAMILY MEMBERS CAN PLAY

- Members of task forces
- Advisory board members
- Program evaluators
- Co-trainers for preservice or inservice sessions
- Paid program staff
- Paid program or policy consultants
- Mentors for other families
- Grant reviewers
- Participants in a needs assessment process
- Reviewers of audiovisual and written materials
- Group facilitators
- Witnesses at hearings
- Advocates
- Participants in focus groups
- Members of committees hiring new staff
- Fundraisers
- Members of boards of trustees
- Participants at conferences and working meetings
- Participants in quality improvement initiatives

Families have brought front-end evaluation to policy and program planning that the state couldn't get anywhere else. Their input and participation have given providers a sense of the importance and outcome of their work.

B. McConnell, personal communication, 1993

In addition to maintaining a broad view of the roles that families can have in shaping policies and practices, providers must also be alert to opportunities to seek family involvement. The introduction of a new initiative, program, or service, for example, provides an ideal time to include families.

- When the State Department of Public Health and the North Adams Regional Hospital initiated a new community-based program to support families at risk for domestic violence and child abuse, they formed the Parents' Council. This Council, which includes families who will be served by the program, is charged with ensuring that the program is responsive to family and community needs.
- The Children's Hospital of Philadelphia established a task force to develop a family-centered philosophy of care statement for the hospital. This committee is comprised of family members as well as physicians, nurses, social workers, and staff from housekeeping and security.

Construction and renovation projects often provide the impetus to invite family participation and comment.

- Hasbro Children's Hospital in Rhode Island completed construction of a major new facility in 1993. A key component of planning for the new hospital was the formation of a Parents Advisory Committee to participate in design planning and decision making. The Committee, now called the Family Advisory Council, has continued after the construction, and plays a policy and program development and evaluation role at the hospital.

Conducting a community or program needs assessment also provides an excellent opportunity to seek family input.

The key to designing and implementing successful services is to base them on needs as identified by families rather than on needs perceived by professionals.

Walker et al, 1989

- New England SERVE, a regional planning network for children with special health care needs, invited family members from New Bedford, Massachusetts to assist in developing a process to assess the needs of families in that community. These family members, who represented the diversity of families living in New Bedford, assisted in development of a multilingual family survey, as well as a survey of providers, and also devised telephone interview techniques to increase the number of family survey responses.
- When the U.S. Maternal and Child Health Bureau was planning its system of services for children with HIV and their families, they brought together a group of family members from several cities with a high incidence of HIV infection to describe the kinds of services and supports that were helpful for their families. Feedback from this one day meeting has guided Bureau personnel in policy and program development.

The greatest thing about working with families is that parents expect you to do things just because they make sense!

K. Schrock, personal communication, 1993

- The Institute for Child and Family Development, a family services agency of the Wisconsin Association of Black Social Workers in Milwaukee, used a variety of methods to gather information about the concerns of families in the community who were caring for school-aged children with special needs. In addition to conducting a survey with parents, staff also convened groups of children to learn about their perspectives and needs. One outcome of these meetings was the establishment of a community-based support group for children with special health care needs.

Program evaluation and quality assurance activities also provide important opportunities to seek family involvement.

- The Center for the Vulnerable Child in Oakland, California, a program that provides comprehensive services to women with chemical dependencies and their children and families, holds an annual Client Forum to discuss the Center's programming and ways to improve care and services.
- At Phoenix Children's Hospital members of the Parent Advisory Council and the hospital's two Family Support Coordinators participate in continuous quality improvement activities. Recent discussions between families and professionals resulted in the development of a bereavement program for families, a pilot noise reduction effort, and focus groups at which families and staff explore the meaning of quality for the hospital.

Both preservice and inservice training programs are enhanced by including families as faculty members.

- The University of Vermont and Parent to Parent of Vermont have developed a program to enable medical students, residents, nurses, social workers, physical therapists, and early intervention specialists to spend time with families of children with special needs in their homes and communities. Participants describe these non-clinical experiences as "invaluable" and as "essential for a well-rounded perspective."
- Parents Helping Parents, a community-based Family Resource Center in Santa Rosa, California, sponsors "lunch and learn" workshops for practicing physicians at area hospitals on supportive ways of giving a difficult diagnosis to parents.

As these examples demonstrate, involving families in program and policy activities brings positive results. When providers see the benefits of participation they seek ways to ensure that families' perspectives and expertise become a continuing part of discussions. Often what begins as a request for short term family involvement evolves into long term participation.

Families in Advisory Roles: The Benefits

> "Collaboration means that no one interest group is always right. It means taking what you think, and what I think, and what someone else thinks, and coming up with something that works for everyone." (B. McConnell, personal communication, October, 1993).

Parents often ask these exquisitely simple questions like, 'Why do you do it that way?'. . . . it may challenge something we've held very near and dear for a long time but we couldn't answer if our lives depended on it. It's just how we've done things!

B. Balek, 1992

The benefits of involving families as consultants and advisors are enormous. In a recent survey of state health departments conducted by the CAPP National Parent Resource Center (1993), respondents overwhelmingly endorsed the concept of including families in advisory roles and identified many benefits — to the program, to the providers, and to the families themselves. A comparable survey by the University Affiliated Programs (UAPs), interdisciplinary training programs preparing professionals for careers in the field of developmental disabilities, reports similar findings. When asked, "How has having parent(s) involved in UAP activities been helpful?" respondents' replies included:

- "They give us among the most important perspectives in planning and implementation of our work."
- "She has made a world of difference. The perspective she brings helps bridge the gap between the university and the community."
- "They have kept us all honest."
- "Very helpful in making training relevant and realistic."

Of primary importance is the essential role that families play in improving quality. As consumers, families experience the system from a unique perspective. Their observations, insights, and ideas are powerful tools for enhancing quality (Vosler-Hunter & Hanson, 1992).

Because families see things through fresh eyes, they may see problems or inconsistencies to which professionals have become accustomed. They also often see solutions that may have eluded providers. As families caring for children with special needs in the community, they are constantly required to adapt, to create solutions with few resources. Their resourcefulness can be an enormous benefit to the service system.

The involvement of families also helps to ensure that the design of programs and the services offered really meet family needs. When families are participants in planning and decision making the likelihood of developing effective, responsive services is greatly increased.

Parents were tremendously helpful in the design process. Every comment they made had enormous meaning. For many of them, serving on the Council was an altruistic act, because they had experience with a child who had been ill, and they were hoping to create a building that would help other parents through hard times.

L. Acton, 1994

Families can also often advocate for system and program changes in ways that professionals cannot. As employees, providers may have limited opportunities or avenues to express concerns or to implement changes. Families do not face these same restrictions.

Families are tireless advocates. They have a vested interest in making things better, not only for their own families, but for other children and families as well. For many, participation at the program and policy level provides an opportunity to give back to the system, to reciprocate for the care that their child and family have received. They are committed to excellence, and their energy is unflagging. They bring fresh perspectives, creative solutions, and limitless creativity.

> "It's about waving a flag, getting on a soapbox, about being a part of the system and realizing, indeed, you have a voice that can be heard and it can make a change no matter how little or big it is. You have to be involved." (Callendar, 1994, p. 8)

When families work side-by-side with professionals to design and implement programs, both are enriched. Professionals, who have only seen families in the clinical setting, learn more about family strengths, resources, and individuality. Families develop new skills, competence, and confidence. Both develop an expanded view of the other and gain an appreciation of the expertise and experience that each brings.

> "One outcome of this [Parent Participation] program is greater ownership, on the part of families, in evaluation and adapting CSHCS services and making Solomon-like decisions that balance the very real needs of children and families against the very real need of the state to use its limited resources as efficiently and effectively as possible." (B. McConnell, personal communication, 1994)

Finally, families are visionaries. Their dreams are not tied to bureaucratic limitations. Their ideas and hopes for their children, their families, and their communities provide challenge, inspiration, and guidance.

> "Having a vision is not just planning for a future we already know how to get to. It is daring to dream about what is possible." (Vohs, 1993, p. 63)

Tips from the field

Judy Quest, the parent coordinator for Part H in Nebraska, recommends beginning each family/professional meeting with a family story to build understanding of the realities of caring for a child with special needs, and to remind participants of the real purpose of their work.

Families in Advisory Roles: The Barriers

Family participation is still treated as a side issue in many states and communities — a nice but not necessary part of changing the system for the better. And the belief that the system belongs to the professionals who are employed by it is tenacious.

B. Friesen, 1992

Families bring immense expertise to their relationships with professionals. They know their own child and family intimately; often they also know the concerns and issues facing other families in their community. The effectiveness and quality of programs for children and families can best be measured by how well those programs actually meet family and community needs. What better way to initially define community needs, develop a responsive program, prepare personnel to provide appropriate, supportive services, and evaluate outcomes and satisfaction than in partnership with those who are being or have been served by the program?

In spite of the obvious benefits of consumer participation, however, families are not serving in advisory capacities in significant numbers. In large part, the exclusion of families from these roles has been the result of professional attitudes and expectations. In addition, some parents have been reluctant to assume these advisory roles. Even when families and professionals want to work together, they are often constrained by administrative and logistical barriers. Finally, and perhaps most importantly, these new partnership relationships involve risk and require change for providers, for families, and for institutions. Involving families in advisory roles is hard work.

PROFESSIONAL ATTITUDES

"This Isn't What I Learned In School."

In large part, professionals in the health, mental health, social service, and education fields were not trained to engage in partnership relationships with families. In fact, because so many professional training programs are derived from a medical model that is deficit-based, many human service professionals have never had the opportunity to learn about the strengths of families. It is not surprising, therefore, that these professionals might question the efficacy of involving family members in collaborative endeavors. For professionals whose training emphasized keeping a professional distance, and warned of the pitfalls of "over-involvement," the notion of families as partners is especially threatening.

"Who's More Knowledgeable, Anyway?"

Professionals, especially those in the medical field, have also traditionally been taught that they are the "experts." Years of schooling and intensive training have reinforced this belief and promoted an autonomous approach to decision making. Shifting to a collaborative relationship with families based on respect for their expertise and insights requires a fundamental reorientation.

When you allow yourself to be open you don't take parents' anger personally. You know it's institutionally based.

B. Torres, personal communication, 1993

"Families Have Enough To Deal With. Let's Not Overburden Them."

Most people who choose to go into human service fields do so because they are caring people. Therefore, their instincts are to help, to protect, to make things better for the people they serve. Unfortunately, this attitude can foster dependence and render families passive recipients of care rather than shapers of the programs that affect them. When the families served by a program are poor, speak a different language than staff, or have been stigmatized by an illness such as AIDS, this protective exclusion from the decision making process may be aggravated by the assumption that families have nothing to contribute. This barrier to participation is exacerbated when providers believe that families created their own problems and are dependent on the help of professionals to solve them.

"What's The Matter? Aren't We Doing A Good Job?"

Too often, efforts to initiate family involvement at the policy level, are viewed as a criticism of the providers or of the program. Professionals who strive to provide care and services to families may feel undervalued amid efforts to develop collaborative approaches to planning and decision making. If families then focus on program weaknesses or areas for improvement, professionals may feel angry or resentful that their efforts are unappreciated.

"Parents are able to ask questions when they feel trusted enough or frustrated enough. The parents who feel trusted enough are the nice relationships. They're good dialogues. The parents who are frustrated enough are often in your face. These are less comfortable but equally important . . .We have to be equipped for all different types of reactions and dialogues — some of them comfortable and some of them not." (Balek, 1992).

"If We Give Them A Forum, They Will Make Unreasonable Demands."

Many professionals express concern that involving parents and other family members at the program and policy level will open a "Pandora's box." They fear that families will make unrealistic, unreasonable demands and have expectations of the service system that are unattainable. As guardians, or gatekeepers of the service system, these providers may even feel they have to protect the system from families. Such concerns reflect professionals' beliefs that families do not understand the constraints of a particular institution or system and, therefore, cannot participate appropriately in policy and program discussions. Providers worry as well that families will focus only on the needs of their own child and family and be unable to address broader issues.

Tips from the field

Betsy Anderson, Director of the CAPP National Parent Resource Center at the Federation for Children with Special Needs in Boston, remembers her first experience working at the policy level with professionals in the early 1980s. She emphasizes how important it was when Dr. Allen Crocker, the chair of a particular committee, asked her views and perspectives on issues under discussion. Betsy says, "His behavior demonstrated respect for my opinion, made me feel welcomed and supported, and specifically created the opportunity for my comments."

"We're Already Getting Input From Families."

Many hospitals, agencies, and programs use satisfaction surveys to gain consumer feedback, but rarely involve consumers in designing the surveys (so the right questions are asked) or in finding solutions to the problems that are identified. In some programs and institutions serving children and families a guest-relations program has been instituted. These programs emphasize the importance of staff friendliness and courtesy toward children and families and even seek feedback from families through focus groups, surveys, and individual interviews. While these are important steps in obtaining information about what is and what is not working in the institution, they fail to promote relationships between providers and families, and stop short of actually involving families in problem-solving activities.

FAMILIES' RELUCTANCE

Parents whose children are on federal and state programs have for too long seen themselves only as recipients of services. Too often we don't see ourselves as being able to contribute back to the provider.

K. Odle, 1988

Parents, too, are unaccustomed to working collaboratively with professionals. Even when parents have formed a successful partnership with service providers around their own child's care, they have not extended that partnership to tackling a broader agenda of program and policy development and assessment. Frequently families feel they have nothing to offer in this arena. They question their own expertise.

Families' doubts about what they bring to the discussion may be particularly intense for families who have been underserved by health and human service systems, or whose interactions with the system have been particularly disempowering. Typically these families have had few opportunities to influence policy development.

Even when families are interested in developing new kinds of relationships with professionals they may feel unequipped or unprepared to participate. One mother described the first meeting she attended with professionals this way, "They were all speaking 'duck', and I was speaking 'goose'!" Others may be suspicious about why they are being asked to participate. Another mother described her feelings this way:

> "Several years ago, I received a phone call asking me if I would like to go to Washington, DC. I don't remember who it was, but she said a few words about needing someone who was a minority. There wasn't much time — the conference was to be in a few days. If I was interested, they would send me a ticket. . .They need a minority? Am I a token? I wonder what these people want from me." (Tisdale, 1991, p.2)

Still other family members, especially those who have been outspoken advocates, may find the switch from being an adversary to being a colleague very difficult. Families may feel they are giving up hard-won positions when they

are asked to work in partnership with professionals. The fear of being a "token" or of being absorbed by the system, without a meaningful and substantive role, may leave many families apprehensive about participating.

ADMINISTRATIVE BARRIERS

"Unfortunately, institutions are often characterized by inertia. This inertia can be carried forward by the attitudes of individuals . . . and through the day-to-day rules, regulations, and other formal and informal structures of agencies and institutions. These can conspire to construct real barriers both to the provision of services and the active participation of families in the system." (Jones in McGonigel, Kaufman & Johnson, 1991, p. 83)

Logistical and practical barriers can also impede family / professional partnerships. Successful collaboration requires a commitment of time and money and demands administrative flexibility. For example, programs seeking the involvement of families with young children must provide or arrange for child care; those asking working parents to attend policy sessions must plan meetings for evening hours. Too often, rigid or bureaucratic organizations cannot accommodate these requirements. In speaking about Part H restrictions on reimbursing parents for their participation on the Interagency Coordinating Committee (ICC), one parent wrote:

> "Because of restrictions on parent reimbursement, we do not have fair representation on the Council . . . openings can only go to people who can afford to participate, i.e. middle and upper middle class mothers. No fathers, no lower income parents, no single parents, no one who works outside the home or outside of special education. When parents' expenses are reimbursed, the state reports it as income to the IRS!" (a parent, in Gentili, 1990).

Cumbersome administrative processes often mean that families must wait weeks or months for reimbursement for their expenses. This places an excessive burden on families and may preclude those with limited incomes from ever participating.

Tips from the field

Roberta Sample, a parent member of an Interagency Coordinating Council in the midwest, presented a detailed budget of the expenses associated with her participation on the ICC at a monthly meeting. Since the state does not reimburse families for their expenses, she had spent close to $3,000 of her own money to attend meetings. Roberta reminded the non-parent members of the ICC that both their time and expenses were being paid. Roberta said that while she might be able to make these financial sacrifices, such policies exclude the participation of families with fewer financial resources.

IT'S HARD WORK

"The presence of parents' or consumers' voices in policy-making conference rooms is not a natural phenomenon. When it does exist, it reflects a deliberate attempt to expand the set of traditional decision-makers to include users of services or spokespersons for such groups. Participants in such settings share a common goal of creating a more responsive health care system for children with special health needs." (Epstein, Taylor, & Wells, 1990, p. 1)

Perhaps the greatest barrier to effective family/professional collaboration at the policy level is that it is not a simple thing to accomplish. It requires commitment, energy, and repeated efforts to achieve success. When the culture of an organization is fast-paced and results-oriented, dedicating the necessary time and resources to develop collaborative relationships with families can be very difficult. Often program staff say, "We tried. But it just didn't work. We had a meeting but families didn't come." Inexperience and suspicions on both sides require hard work, tenacity, and flexibility.

Even when professionals and families are committed to working together they may initially need some special help. Giving up traditional ways of relating and developing partnerships based on reciprocity and respect means making oneself vulnerable. When life experiences, cultures, and values differ, the challenges to forming these new relationships increase. True collaboration asks both providers and family members to take a chance. It can be a scary proposition.

"... both parents and professionals must learn new skills and adopt new attitudes to work in partnership in the public arena. For parents and professionals alike, it requires the patience and commitment to form a shared vision, recognize and balance personal and public responsibilities, develop an atmosphere of openness and inclusion in the decision-making process, and careful attention to the differing needs, roles and expectations . . . Both parents and professionals . . . stressed that such collaboration should and does make a difference in promoting change and improving the lives of children." (Vosler-Hunter and Hanson, 1992, p. 5)

Tips from the field

David Jones from the Institute on Cultural Dynamics and Social Change says that breaking down the barriers to collaboration should be a conscious goal, not an accidental occurrence. Families and providers must find the "commonality" in their experiences in order to work together positively. He suggests:

- Hold meetings away from the institution itself. This fosters a sense of coming together on common ground.
- Be as informal as possible. Try to do away with "uniforms" such as suits, ties, and high heel shoes that tend to separate professionals from "just parents."
- Take time to get to know each other. Tell stories and share information that break the ice and help people develop real connections to each other.

Families in Advisory Roles: Making it Happen

The partnership between parents and professionals is based on a realization that everyone's role is important, that what we do together is greater than what any one of us can do separately.

NCCIP, Project Zero to Three, 1989

The single most important factor for ensuring the successful involvement of families in policy and program activities is commitment to the idea. This point cannot be overstated. Without a deeply held belief that families have unique expertise and knowledge and that their participation is essential to improving services, true collaboration will not occur.

Even the most committed professionals, however, face challenges in operationalizing collaboration at the program and policy level. Involving families who have been excluded historically from decision-making roles, who have limited financial resources, who come from different cultures or speak different languages, or who themselves may be in poor health poses special challenges and deserves careful thought and attention. In speaking of efforts to involve families affected by HIV in policy activities, Deborah Allen, Director of the Division for Children with Special Needs, Massachusetts Department of Public Health noted, "There are some special issues involved here, since parents and children face progressive illness and may become less able to devote time and energy to activism even as they become more skillful and knowledgeable about HIV politics and policies." (personal communication, January, 1994.) Being aware of these issues and developing strategies and approaches for addressing them is critically important to implementing successful family involvement at the policy and program level.

Guidelines for involving families as advisors are presented below. Discussion and examples of each of these principles, as well as tools and resources for translating them into practice follow.

GUIDELINES FOR FAMILY PARTICIPATION AT THE POLICY AND PROGRAM LEVEL

- Maintain a broad view of collaboration.
- Expand the definition of successful family involvement.
- Use innovative ways to identify and recruit families.
- Look for opportunities to promote family involvement.
- Provide training and support to both families and professionals.
- Address logistical barriers comprehensively and creatively.
- Be aware of parental burn out.
- Believe family participation is essential.

MAINTAIN A BROAD VIEW OF COLLABORATION

Family input at the policy and program level can be as formal as the development of a paid staff position for a parent consultant, or as informal as a coffee hour on a hospital inpatient unit where families share their perspectives on the hospital experience. It can be an ongoing process, such as a monthly advisory committee meeting, or a one-time activity such as a focus group on a particular topic. All of these approaches are valid and each can yield valuable information from families. What is important is that families' input is sought and valued, and that policy, program, and practice decisions are shaped by the opinions and perspectives of those they intend to serve.

Tips from the field

Mary Huber, the Director of Partners in Health, a New York State Health Department project that assists families caring for children with special health needs, has identified the following as essential for successfully involving diverse groups of families, especially those from isolated rural areas and from different ethnic groups, in policy activities:

- Have a basic philosophical belief in the value of families' expertise and knowledge.
- Have the money "up front" to pay for families' expenses and to provide consulting fees.
- Be open about cultural differences between families and staff.
- Keep families apprised of project happenings through newsletters and mailings.
- Show appreciation for families' roles as advisors.
- Maintain a feedback loop — as parents succeed, it becomes a natural motivator for other parents.

- The Parent-Infant Resource Center of Georgia State University in Atlanta involved families in all phases of the development and dissemination of educational materials for families of low birth weight infants. In order to ensure input from a broad range of families, not only those who served on the project's advisory committee, the staff held informal focus groups in neighborhood health clinics and Head Start centers, and "piloted" the materials with families in subway stations, bus stops, and laundromats. Comments from families in these informal interviews resulted in substantial changes in the content and format of the materials.

- The Director of Family Relations at Children's Hospital of Philadelphia holds joint meetings with families whose children are in the hospital, clinical staff members, and housekeeping staff to discuss what is working and what needs improvement on each of the hospital's units. An outcome of these meetings has been the development of two small unit-based Family Resource Libraries and the planning for a third.

- In Mississippi, the Adopt a Policymaker Program brings together families of children with disabilities and state legislators. The program is designed to encourage positive communication and enhance both the policymaker's and family's understanding of one another. Families visit "their" policymaker at the Capitol, send them letters, birthday cards, and children's art work, and invite them for dinner. Those who participate in the program believe that this personal contact will enable policymakers to better understand the unique needs and strengths families have when disability is a part of every day life.

A powerful way to ensure that the perspectives of families help shape program development and clinical practice is through involving them in training activities for professionals. Families' participation can be a one time presentation, or an ongoing part of preservice preparation for professionals-in-training. Finding opportunities for families and staff to participate together as learners also promotes collaboration and provides a forum for the sharing of perspectives and expertise.

- At Wheelock College in Boston, the position of parent advisor has been added to the faculty for teaching students in the fields of child life, early intervention, and education of young children with special needs.
- The Parents as Educators Program at Children's Hospital of St. Paul gives medical students and residents a chance to meet with families over lunch once a month to learn their perspectives and experiences in caring for a child with special health care needs.
- The state of Maryland developed a request for proposals (RFP) as part of its Part H early intervention program. Only parent/professional training teams were eligible to apply for funding to develop training materials and sessions on building collaborative relationships during the Individualized Family Service Plan (IFSP) process. Another requirement of the RFP was that both staff and families receiving early intervention services participate in the training. Family Support Network Coordinators in each of the state's regions are responsible for identifying families to participate in the training sessions.

Additional ideas for involving families as training partners are presented on page 16.

Family advisory activities can take many forms. Policy makers, program planners, and service providers should maintain a broad view of collaboration and seek to develop multiple opportunities for families to share their perspectives and expertise.

PARENTS AS TRAINING PARTNERS

SOME WAYS FAMILIES CAN PARTICIPATE

- **Determining training needs**. Families can help determine training needs of providers by participating in focus groups, surveys, interviews, or brainstorming sessions.
- **Designing and producing training programs**. Families should be invited to participate in the development of the training design. They can brainstorm activities, produce media and materials, and review and comment on drafts of curricula and materials.
- **Conducting training programs**. Families can be involved in many ways — conducting programs independently or as co-trainers; participating on panels; being available as information resources; offering a consumer's point of view.
- **Receiving training**. Families should be invited to attend when training sessions are offered. Families and providers can better understand each others' roles when they spend time together in learning activities.
- **Evaluating training**. Families can help evaluate training programs by attending pilot sessions, reviewing materials, and conducting pre- and post-training surveys.

KEY PRACTICES

- **Involve families who represent a wide range of experience**. Include those who are currently receiving services, as well as "veteran" parents. Strive to include families who represent a diversity of viewpoints, as well as a variety of racial, ethnic, and cultural backgrounds.
- **Make the process accessible**. Mutually convenient times and places for training are essential. This may mean that training is held outside traditional work places and business hours.
- **Pay families for participating**. Offer families reasonable payment for developing, conducting, reviewing, and evaluating training programs, as well as reimbursement for child care, travel, and other expenses.
- **Offer supports**. Offer to help families acquire skills needed to participate in the development and delivery of training. Other useful supports might include clerical services, work space, and photocopying.

(adapted from Parents as Training Partners, Project Copernicus)

When the Parent Advisory Group was meeting at the hospital we were getting good attendance but there was something missing – a feeling. We changed the meeting place to my house and the attendance soared.

L. Williams, 1992

EXPAND THE DEFINITION OF SUCCESSFUL PARENT INVOLVEMENT

The traditional view of families as advisors is often that of parents attending committee meetings each month. However, the expectation of this kind of regular attendance over a long period of time may present barriers to families whose children's health is precarious, who are themselves sick, who have other highly stressful elements in their lives, or who already have multiple commitments at home, at work, or in the community.

- The Parents and Children Together Program (PACT) at the Children's Hospital of Buffalo, New York provides primary health services to infants who are drug-exposed, and support services to their families. Because of the multiple demands facing many of the families served by the program, a Parent Advisory Board proved to be an ineffective format for receiving their input on program and policy issues. Instead, a suggestion box was instituted and time was devoted during parent support group meetings to getting program feedback from families. In addition, the program's Resource Mothers (trained home visitors from the community) are encouraged to seek suggestions from families about programmatic directions and policies.

- MassCARE, a statewide system of care for children affected by HIV and their families, has a strong commitment to ensuring that the voices of families are part of policy and program development. MassCARE staff have developed many opportunities for family participation including: hiring a Parent Consultant, the mother of a child with HIV infection, to coordinate the family-to-family activities and support network within the state and to provide ongoing expertise on family issues to the program staff; developing a family planning/advisory committee to encourage input from a broad range of families in project activities; and inviting families to participate on administrative committees such as the MassCARE Coordinating Committee and the Legislative Task Force.

  One of the essential goals of the Parent Consultant and the MassCARE Director was to ensure that the mechanisms for family participation were flexible and responsive to the issues confronting families affected by HIV. They asked families about the necessary supports to make their participation possible (e.g. planning committee meetings were held in the morning, children could come, food was provided). They demonstrated their respect for families' expertise by paying them for their participation ($25/two hours). And most importantly, they conveyed understanding about the stress that families face by saying, "We will be here each month. Come when you can. When you don't come we will be concerned about you." This message recognized the demands of these families' lives and acknowledged that their inability to participate in every meeting did not mean lack of interest.

Involving families in a one-time or short-term advisory activity enables professionals to hear a broad range of perspectives without overburdening families who have other demands on their time.

- The Office of Children with Special Health Care Needs (OCSHCN) in Arizona has developed a range of ways to involve families throughout the state in advisory roles. Rather than hire one full time parent consultant, funds have been used to contract on a short term basis with hundreds of families throughout the state. Some families are involved in ongoing advisory work, others participate in time-limited activities. For example, in a recent survey, OCSHCN staff asked families what issues they had expertise in or would like to work on to improve community and state support for children with special needs and their families. Based on the families' responses, teleconferencing teams were established for small groups of parents and professionals to discuss particular issues. The teleconferencing format enables families to participate from their homes, yet ensures that family perspectives and opinions inform all discussions.

- When the U.S. Army began planning for comprehensive early intervention services at its overseas locations, planners engaged in a needs assessment process that incorporated a series of brainstorming sessions in the communities to be served by the program. In each community, a representative from the early intervention program met with a group of professionals and parents to gather information about the needs and resources of the community, to identify barriers to a successful early intervention program, and to identify strategies for overcoming the barriers. Family members were invited to participate in the earliest information gathering meetings, to ensure that their perspectives were heard from the beginning of the assessment and planning process.

Tips from the field

Randi Malach, Project Director of the Pathways to Understanding Project at Southwest Communication Resources in New Mexico, has found that culturally homogeneous focus groups are very effective formats for gathering information from families whose culture values consensus decision making. In a focus group, no one person is put on the spot or asked to speak for the group.

Developing flexible approaches for receiving input from families promotes the involvement of consumers and enables both families and providers to feel successful. The tool, "Families as Advisors: Broadening Our Vision" lists some ways that families can participate in program planning and evaluation for brief periods of time.

FAMILIES AS ADVISORS: BROADENING OUR VISION

There are countless ways that families can serve as advisors. Below is a list of some ways to receive input from families informally and for brief periods of time.

- Convene focus groups of families as specific issues arise.
- Hold a monthly family/staff coffee hour.
- Ask families to "host" a professional-in-training for dinner.
- Solicit family input in community and program needs assessments.
- Include families on site visit teams to other programs.
- Hold brainstorming sessions with families before developing educational materials.
- Have families review drafts of all written materials.
- Include a family panel during orientation for new staff.
- Conduct follow-up phone calls with families after hospital discharge.
- Ask families to assist in translating materials.
- Develop, with families, a parent satisfaction survey.
- Develop a "breakfast (or lunch) with the director" program for families.
- Keep a suggestion book in the waiting room, so families can record their ideas.
- Ask families to accompany staff when they meet with funders and other community groups.
- Invite families to present at inservice programs for staff.
- Set up "exit interviews" with administrators when families are leaving the hospital or program.

TIPS FOR RECRUITING FAMILIES

- Ask other families who are already involved if they have a friend who might be interested in participating.
- Ask providers to identify families.
- Contact local or statewide parent-to-parent organizations.
- Post notices in appropriate languages on bulletin boards in waiting areas in clinics and in hospital emergency rooms.
- Post notices in appropriate languages on bulletin boards at educational, recreational, and social service programs serving children and families.
- Include information about opportunities for families to participate as advisors in the program's or hospital's consumer satisfaction surveys.
- Ask families who participate in NICU reunion gatherings.
- Develop radio and TV public service announcements in the language of the communities you are trying to reach.
- Place a story in community newspapers.
- Use "key informants" — people in the community who are knowledgeable about children with special health care needs and are a link to other families and family groups.
- Ask community and church leaders.
- Send notices to social and cultural clubs in the community.
- Place posters in community locations — at large employers, churches, housing projects, gas stations, social service agencies, and kindergarten registration.
- Send a letter home with school children.

USE INNOVATIVE WAYS TO IDENTIFY AND RECRUIT FAMILIES TO PARTICIPATE

As providers embark on collaborative work with families, their first challenge may be finding families to participate. Often, they are unsure of who to involve and how to initiate this new kind of relationship.

- Construction of a new building was the impetus for bringing families and providers together to implement family-centered change at the Children's Medical Center in Augusta, Georgia. Clinical and administrative staff, however, had no experience in working collaboratively with families at the planning and policy level, nor in identifying families to participate. The hospital hired the Institute for Family-Centered Care to initiate this collaborative process. As a first step, the Institute facilitated a two day retreat for approximately 75 professionals of many disciplines and parents to develop a philosophy and values statement for the Medical Center. Retreat participants worked in small groups to generate over 45 values statements and the group as a whole voted and selected the ten deemed most important for the hospital. These statements were subsequently endorsed by administrative groups and departments within the hospital. Comments from participants reflect the success of this collaborative retreat.

  - "The diversity was great. I especially appreciated how each discipline was placed on equal footing so that sharing was prevalent. Just including parents broke down barriers and increased collaboration."
  - "As a parent and a voice — I feel I was heard and that I heard others."
  - "The parents who participated showed how much health care professionals affect people's lives. This has been a wonderful collaborative learning experience."

  Providers must develop a broad range of strategies for identifying and involving families. These varied approaches are especially important as agencies and institutions seek to involve families who have not traditionally served in advisory roles.

- In 1988, the Maternal and Child Health Bureau wanted to learn about service delivery needs from families affected by HIV and AIDS. Because of the stigma and isolation associated with the disease, identifying families to participate was especially challenging. Service providers in high incidence cities were contacted and asked to identify families for this meeting. They

Tips from the field

David Jones from the Institute on Cultural Dynamics and Social Change suggests contacting community, regional, or state organizations that serve particular cultural groups when seeking input from a broad group of families. For American Indians there are often inter-tribal organizations or urban Indian centers. The National Council of LaRaza can assist in identifying Hispanic groups in various communities. The Mutual Assistance Associations (MAA's) can be a resource for identifying Southeast Asian refugees. Local or state chapters of the Urban League and the NAACP can often assist in identifying African Americans to participate in advisory activities.

Tips from the field

Betsy Anderson has developed some strategies for recruiting new (and perhaps reluctant) families to speak at meetings and conferences. She suggests:

- When you hear someone make a great comment at a meeting, over the phone, or just in conversation, TELL THEM. Help others to see themselves as people with insights.
- Even if you don't have a particular time, place, or topic in mind, mention the POSSIBILITY of speaking. Plant seeds for the future.
- When you do have a specific request, be enthusiastic.
- Discuss a variety of supports with families if they are hesitant about taking on this new role. These might include:
  - brainstorming, listening to their ideas, and offering feedback;
  - thinking with them about the session — who might be present, what is the context of their remarks;
  - identifying areas they might not be comfortable discussing and suggesting phrases such as "You'll have to ask me that one in another ten years!" or "That's a tough one, maybe someone else has a good response" to deflect difficult questions;
  - going with them to the presentation.

were also asked to serve as supports for these family participants — to accompany the families to Washington, to assist with travel and logistical arrangements, and to be the family members "silent" partners during the meeting to provide emotional support. In order to protect the anonymity of the participants, pseudonyms were used when airline tickets were purchased and only first names were used during the meeting.

- When the Partners in Health Project (PHP) in New York was hoping to reach families of children with special health needs from a wide variety of cultural groups to participate in Partners in Policymaking training, they sent letters to all parent-to-parent networks statewide as well as tribal reservation and urban Indian health clinics, foster parent organizations, and agencies serving families from many different cultural backgrounds. PHP also developed a press release for media whose major readers/viewers were families from culturally diverse backgrounds, asked local health units to distribute information to families they knew, and contacted local community leaders to encourage families to participate. While the information they distributed did not exclude anyone, it emphasized that families from culturally diverse backgrounds were particularly welcome.

When recruiting families for advisory roles remember that it may take time to establish trust and understanding of these new expectations. This may be especially true if families have had no previous experience as an advisor, if previous experiences have been negative, if English is not their first language, or if families are from a culture where extensive collaboration with professionals is not the norm (Hanson &, Lynch, 1992). Remember, as well, that some families may require more support and preparation time prior to attending meetings or participating in advisory activities. Finally, after families have been identified and recruited be sure to show appreciation for their efforts, and to publicly thank them for their participation.

The tool, "Tips for Recruiting Families" presents some ideas for identifying families to serve in advisory roles. "Strategies for Working with Families Who Speak Languages Other Than English" presents strategies for developing collaborative relationships with families whose primary language is not English.

STRATEGIES FOR WORKING WITH FAMILIES WHO SPEAK LANGUAGES OTHER THAN ENGLISH

- Identify someone who is of the family's culture and speaks the family's language to facilitate family participation.
- Provide explicit instructions about what the family will be expected to do.
- Ask the family if they want an interpreter and involve them in the selection of interpreters.
- Strive to offer interpreters for all the program's activities, not just at special times.
- Use the same interpreter at each meeting so that a new interpersonal relationship does not have to be established each time.
- Identify interpreters who understand the subject matter being discussed — for example, someone who understands terms and professional jargon commonly used.
- Encourage family members to bring someone they know to interpret if they prefer.
- Invite a bilingual veteran family member to sit with a new family participant to translate and offer support during and after meetings.
- Provide all written materials in the family's preferred language. In addition, materials can be offered in other formats, such as videotape and audiotape.
- With families' permission, tape record sessions and meetings in addition to keeping minutes some families may not be literate in their own language.

When the official role of parents is reflected in all our organizational structures and standards, then it's not just one parent advisory committee out there. It starts to get woven throughout the organization. And that's what we're trying to do – to develop a tapestry in which all the different threads add to the richness of it.

B. Balek, 1992

LOOK FOR OPPORTUNITIES TO PROMOTE FAMILY INVOLVEMENT

A commitment to family/provider collaboration means being vigilant about opportunities to promote consumer involvement. There are countless ways that families can have input in policy and program development. Providers should be creative and open-minded in identifying opportunities for families to share their expertise and experience.

- High rates of adolescent suicide on the Jicarilla Apache reservation in Northern New Mexico prompted the Jicarilla Apache Tribe to convene a series of community meetings to ask the questions, "What do you think is the problem?" and "What do you think should be done about it?" Over 80 meetings were held and suicide was not among the top ten problems identified by the community. Instead, participants felt suicide was a symptom of other problems such as substance abuse and domestic violence. The Community Resource Action Group (CRAG) was then formed to develop and guide programmatic responses to these community concerns. CRAG, which meets monthly, is comprised of tribal council members, service providers, and a broad range of community residents. Among CRAG's earliest initiatives was the development of a domestic violence code for approval by the tribal council. A domestic violence prevention program has subsequently been developed based on the community's shared understanding of domestic violence.

- In Michigan, the selection and orientation of new physicians and other staff for the Title V program of the Department of Public Health provided an opportunity to seek the involvement of families. Families sit on all the committees involved with the hiring and training of new staff.

- ACTG 076 was a research study that demonstrated dramatic reductions in the rate of transmission from women with HIV infection to their newborns. When the results of this study were announced, policy makers were eager to develop recommendations for implementing this important finding. Recognizing how essential it was that the perspectives of HIV infected women help shape these policy recommendations, the Maternal and Child Health Bureau provided support to the Institute for Family-Centered Care to convene a day-long focus group of women to discuss issues related to 076. A report was developed based on the women's discussion and disseminated to key decision makers.

Tips from the field

Dr. Eileen Ball of the University of Illinois at Chicago invites families from a family-to-family support program for families of children with special needs in the inner city to be guest faculty in the Graduate School of Social Work and Education. She asks them to speak "from the heart" and to address the question, "How can we (as professionals) be better allies to you and your child?" She also gives these suggestions to parents to help them plan their presentation: 1) briefly describe your life story; 2) describe an actual event involving a service provider and you or your family that exemplifies something that you never want to happen again — either to yourself or to anyone else; and 3) share an actual event that demonstrates actions you find helpful and want to have happen more often.

- When the Department of the Army began planning for a fully-implemented early intervention program in South Korea, it was apparent that staff needed more information about the needs of families with Korean spouses. As part of the needs assessment process, funds were allocated to hire local Korean-American family members to share insights and help build bridges to the Korean-American communities to ensure that the early intervention services would be relevant to the concerns and priorities of these families.

- The search committee for a new Pediatric Chief at the University of Vermont College of Medicine consulted with Parent to Parent of Vermont and asked the Director to present recommendations about the qualities they should seek in candidates for the position.

The worksheet, "Thinking About Collaboration: Questions to Consider" presents questions that policy makers and clinicians can ask about opportunities for working in partnership with families.

Tips from the field

Carl Cooley, a pediatrician at the Center for Genetics and Child Development at Dartmouth Medical School always invites parents to present with him when he teaches classes on such topics as spina bifida, Down syndrome, and autism.

THINKING ABOUT COLLABORATION: QUESTIONS TO CONSIDER

- How are families currently involved as advisors in our program?
- Is there a range of ways for families to participate?
- Do we receive input from the diversity of families served by the program?
- What new opportunities exist for involving families?
- What are the barriers to family involvement?
- What strategies can we use to overcome these barriers?

After a while we learned when we're sitting on a committee the terminology that professionals use, such as, 'I have some concerns,' which translates into, 'I'm madder than blazes!' You learn the lingo, you learn the dress. Carry a briefcase whether there's anything in it or not.

a parent in Hanson & Vosler-Hunter, 1992

PROVIDE TRAINING AND SUPPORT TO BOTH FAMILIES AND PROFESSIONALS

Learning to work in collaborative ways requires new skills for both families and providers. Both must receive training and support if these partnership relationships are to be successful.

- Children's Medical Services (CMS) of Florida initiated a Parent Consultant program in the early 1990s as part of the state's five year plan to enhance the family-centeredness of its program. There are currently two consultants, one who works primarily with Title V, the other who works with Part H. One responsibility of the Parent Consultants is to provide technical assistance and support to 18 Resource Parents who are employed by district offices throughout the state. The Resource Parents, whose children have received CMS services, receive training and support for their new roles. A recent day-long training meeting on family/professional collaboration included the Resource Parents as well as their supervisors and the program directors. Among the topics covered at the meeting were: developing working relationships; team building; conflict resolution; and developing change agent skills.

- In response to the tremendous need for families to serve in advisory roles for Part H of IDEA, a Family Leadership Training Program was developed in the state of Michigan. The program, jointly developed by a parent and a professional, provides family members with knowledge and skills in collaboration, family-centered care, advocacy, communication, and conflict resolution. Child care, transportation, lodging and meals, and a stipend are provided to families who participate in the trainings.

Providing families with opportunities to learn what is expected of them in these new roles is essential. It is also important to prepare families for specific activities they may undertake. Simply asking a family member to serve on a committee or to present their perspective at a meeting or conference is not enough. Families must be given thorough descriptions of their role and what the expectations are. Opportunities to practice new roles and skills also contribute to success.

- As part of its training program to enhance the presentation skills of family members, the Partners in Health Project developed guidelines for giving panel presentations. Families are given 10 minutes to speak about their

Tips from the field

Pam Jackson Winton from NEC*TAS, conducted a training for staff and families at the HOPE Infant-Family Support Program in San Diego, California. Because many of the participants were Spanish speaking, all written materials were available in Spanish and English and all sessions were simultaneously translated. Pam remarked that the process required her to be better prepared, to speak more slowly, and to pause periodically throughout her presentation. She commented that it was critical that the person doing the translation was familiar with early intervention terms and issues. Families, many of whom had not participated in such trainings before, rated the session as very successful. An unexpected benefit of the format was that many of the early intervention staff, who are themselves Latino, said it increased the extent to which they felt fully included in a staff training.

Parent support is a broader issue than simply providing the amount of reimbursements or stipends parents need to be able to participate in the first place. The quality of parent participation can and should be enhanced through in-service training, orientation, and providing for mentoring relationships with experienced parents.

M. Gentili, 1990

child and family. They are asked to describe the major influences and cultural factors that are important to them, and "make them who and what they are." Families are also asked to describe what they want from professionals, especially with regard to cultural sensitivity. The guidelines encourage families to practice their presentations one or two times and to bring photographs of their children when they deliver the actual presentation.

"Veteran" parents are a great resource for guidance and training for families newly serving in advisory roles. Identifying experienced mentors to provide encouragement and support to novice families as they develop skills in new areas brings very positive results.

- The National Pediatric HIV Resource Center and New England SERVE developed a publication on indicators of family-centered care in programs serving children and families affected by HIV. A working meeting was held during the development of the publication to receive input and comments from providers and family members. In order to support the family members, many of whom had never participated in a national meeting, experienced parents from the broader network of parents caring for children with special health care needs were assigned as mentors to the families. There was one experienced parent for every four family members from the HIV network. Prior to the meeting, the mentors telephoned the families, described the meeting and what would be expected of participants, and answered questions. During the meeting the families and mentors gathered daily for a meal and to discuss issues related to their participation in such a meeting. Both the family members and the experienced mentors participated in the working groups.

- When families of children with HIV infection were first asked to serve on federal grant review panels they were partnered with parents of children with other special needs who had experience with the grant review process. Both the new and the experienced parents received the grant applications and over several weeks of reimbursed long distance calls jointly reviewed the grants. When the review panel convened, both sets of parents attended. The experienced parents played a supporting role to the first-time participants, providing encouragement and role-modeling when appropriate.

When families join a committee or board they should receive a thorough orientation and the ongoing training they need to participate fully and comfortably. They should receive infor-

Tips from the field

Mary Wilson, an enrolled member of the Keweenaw Bay Ojibwe Tribe, and a parent member of the Wisconsin Council on Developmental Disabilities, suggests that administrative boards and committees initiate activities and develop educational opportunities to learn about the many racial, ethnic, and cultural communities that exist in their region. By educating themselves, these policy makers and service providers will be better equipped to collaborate with families from many diverse backgrounds.

mation about the work of the committee, and also about the "culture" of the organization and the "dos" and "don'ts" of their new role. Topics to be addressed in an orientation should include:

- Speaking the organization's language — Jargon 101
- Who's who in the organization and on the committee
- How to prepare for a meeting: what to wear, what to do ahead of time, what to bring
- How meetings are conducted: Robert's Rules of Order, committee reports, approval of minutes
- Communicating collaboratively — techniques for getting your message across:
  - telling your story so people listen
  - how to ask tough questions
  - what to do when you don't agree
  - listening to and learning from other's viewpoints
  - thinking beyond your own child and family

"Guidelines for Successfully Involving Family Members on Boards, Task Forces, and Committees" presents key points to remember when inviting families to participate as committee members.

Tips from the field

Brunilda Torres, Director of Family and Community Support, CSHCN, for the Massachusetts Department of Public Health says that mentoring for these new collaborative roles should occur across the family/professional spectrum. Not only should parents mentor other parents, and professionals other professionals, but families and professionals should also serve as mentors to each other. This will enhance the development of mutuality and reciprocity in the relationship and deepen the commitment to working in partnership.

GUIDELINES FOR SUCCESSFULLY INVOLVING FAMILY MEMBERS ON BOARDS, TASK FORCES, AND COMMITTEES

- Develop a plan for identifying families to participate.
- Support staff in developing an understanding of the value of family participation.
- Provide orientation to both family members and staff about the issues, participants, and process.
- Provide convenient meeting times and locations for family members.
- Compensate families for their time, expertise, and expenses.
- Clearly identify a staff person to be the primary contact person for reimbursement and other issues. Be sure she/he understands that timely reimbursement is essential.
- Provide accurate, timely, clear, jargon-free, and appropriate information prior to meetings.
- Provide all materials in the families' preferred languages.
- Provide clear information about the goals of the board, task force, or committee and the role of individual members and the roles of family members.
- Match veteran parents with inexperienced family members to ensure that new members feel supported in their roles as advisors and have the opportunity to share their new and fresh ideas.
- Balance membership on committees between families and professionals. One family member on a committee is not enough.
- Ensure diversity among the membership by recruiting broadly from the community and the population the program serves.
- During and after meetings, specifically recognize the value of family participation.
- Consider incorporating a "family leave" policy so that family members can choose an inactive role but maintain their membership should family circumstances require some time off.
- Consider shared leadership — parent and professional co-chairs.
- Recognize that some family members may require more support than others to participate in a meaningful way.

ADDRESS LOGISTICAL BARRIERS COMPREHENSIVELY AND CREATIVELY

- The Maternal and Child Health Bureau brought a group of family members to Washington to discuss service delivery issues in HIV care. After the meeting, the airport was closed due to a snow storm. Fortunately a service provider was in the airport at the same time and was able to use her credit card to pay for hotel rooms for the families that evening. If she had not been there the families would have had to spend the night in the airport.

- The mother of a child with special needs traveled to Boston to participate in a national advisory committee meeting. Her room was to have been paid for by the organization hosting the meeting. However, when she checked in the hotel demanded a credit card (which she did not have) before they would allow her to register.

As these examples demonstrate, logistical and practical barriers to family involvement are very real. However, with commitment, creativity, and careful planning they can be overcome. When planning for family participation, it is essential to remember:

- Families of children with special needs need sufficient time to make child care arrangements when they must be away from home.
- Child care for children with special needs may be difficult to find and is usually expensive.
- Most families do not have access to fax machines and computers.
- Some families do not have telephones.
- Many families do not have credit cards or ATM cards.
- Many families rely on public transportation.
- Some families do not have bank accounts.
- Some families have never traveled out of their home community.
- Some families may require special physical supports.

These factors must be considered whenever collaborative activities are planned. They have implications for how information is communicated to families, when and where meetings are held, and how parent advisory activities are financed. Fortunately, with thought and a little effort most of these issues can be easily addressed. The key is for providers to realize that the

Tips from the field

The Parent Participation Program of the Michigan Department of Public Health developed a brochure to help families manage the logistics of traveling to and attending conferences. The brochure is designed to give families the information they need to negotiate airports and hotels, budget travel expenses, and choose conference sessions.

supports available to them in a professional setting, most often do not exist for families. In order to ensure that the collaborative relationship is truly an equal one, providers must pay close attention to the realities of families' lives and plan accordingly.

- The bylaws for the ICC in Arizona, state that the Council will offset financial obligations that parents incur as a result of their participation and will develop policies and procedures for timely reimbursement for travel expenses, child care, respite or related special services. Because it is state policy to pay 85% of all travel reimbursement and per diem in advance of trips, the policy has been extended to families serving on the Council. In addition, the Council purchases airline tickets in advance and pays registration fees prior to conferences.

- To facilitate the involvement of families in national advisory activities, the Director of the Comprehensive Pediatric AIDS Program in Ft. Lauderdale, Florida prepared a short orientation for family members traveling to a meeting of the Ryan White Title IV projects in Washington, D.C. She talked with them about what the meeting would be like, who would be there, and what their role in the conference would be. In addition, she provided information on traveling to and from the airport, registering in a hotel, and what the weather would be like. For these families, who had never traveled before, this information was supportive and enabled them to feel secure in this new endeavor.

Tips from the field

Josie Thomas, Director of Family Issues at the Institute for Family-Centered Care, suggests always checking with families ahead of time to find out if they want their reimbursement and per diem expenses paid by check or in cash. If families do not have bank accounts, are in a place where check cashing is difficult, or need money to pay immediate expenses, providers should have cash available. By having families sign a receipt when they receive the cash payment, appropriate records can be maintained.

A guiding principle of family participation is that all families should receive comprehensive support "up front." Too often, only families who are perceived as "needy" are offered financial support. This is demeaning for those who are singled out and places a great burden on those who are asked to pay their own way. No family member — regardless of their perceived financial status — should ever be asked to pay the costs of their own participation or to wait for reimbursement for their expenses.

- The Tsunami Project, of the Office for Children with Special Health Care Needs in Arizona contracts with parents statewide for a variety of advisory activities. In addition to reimbursing for expenses, the state offers all parents $10 an hour for their participation. However, because many families do not want to jeopardize their SSI payments by earning too much income, some choose to contribute their advisory expertise on a voluntary basis. The state keeps track of the contractual dollars each parent advisor has earned, and alerts them if they are reaching the SSI cut off point.

Tips from the field

Felicia Jordan, co-director of Project Uptown in Detroit, says to always check "cultural times" and religious holidays when scheduling meetings that involve families. For example, Friday nights and Saturdays are very important times for some cultural groups. Advisory activities scheduled at those times may preclude the participation of many families.

- Both consumers and providers serve on the Board of Directors of the AIDS Policy Center for Children, Youth, and Families (APC). To assist with the expenses related to their participation, the APC established an "800" number for board members to use in contacting the Washington-based office, and provided a telephone calling card account number for members to use when conducting APC business from their home telephones.

Arranging for financial support for families to participate in collaborative activities may require restructuring of program budgets, or looking for resources from community groups or from businesses or corporations. In state and federal agencies where funding mechanisms for family participation are cumbersome and slow, funds can also be administered contractually through a community organization.

- The Maternal and Child Health Branch of the Division of Public Health in Georgia and the CAPP/NPRC Project of the Federation for Children with Special Needs developed a collaborative relationship to facilitate the hiring of a parent of a child with special needs as the Coordinator for Parental Support and Involvement for the state. CAPP/NPRC provided the funding for the position and for associated travel expenses. The Maternal and Child Health Branch provided office space and clerical support for the position.
- There is no civil service category for parents in the state of Michigan. When the Department of Public Health wanted to hire a parent to direct the statewide Parent Participation Program, administrative staff contracted with the Children's Hospital of Michigan. The Parent Participation Program director receives her salary and benefits through the hospital, and the state contracts with the hospital for her services.

Whatever solutions are found to address these financial and other logistical issues, they are sure to require flexibility on the part of the providers. Maintaining a sense of humor and commitment to this collaborative work is essential to success.

The tool, "Traveling to Conferences and Meetings: Making Family Participation Successful" presents some of the logistical issues that must be addressed when involving families in advisory activities, especially those that require out of town travel.

TRAVELING TO CONFERENCES AND MEETINGS: MAKING FAMILY PARTICIPATION SUCCESSFUL

- **Identify all the costs associated with family participation**. Include travel, transportation costs to and from airport, hotel, meals, registration fees, child care, and any other incidental expenses.
- **Cover expenses up front.** Purchase tickets ahead of time, provide cash for family per diem expenses, create a master account at the hotel using your credit card. Explain what the per diem will and will not cover. If there are expenses you will not cover (e.g. movie rentals and mini-bars in the hotel room), tell families ahead of time.
- **Plan ahead**. Airplanes, taxis, and hotels are not set up to be flexible. Therefore, you must be creative, thorough, and vigilant in planning so that families are neither excluded nor embarrassed when negotiating these systems.
- **Develop a policy for honoraria or consulting fees for families.** If professionals are being paid for their participation, families should be as well. If families are asked to speak at conferences they should receive an honorarium.
- **Provide thorough preparation for families prior to the meeting**. Send information about the meeting and families' roles. If materials must be reviewed, send them in time. Review families' understanding of the information and what is requested of them. Provide complete logistical information — how to get from the airport to the hotel, who to contact and how to contact them in case of problems.
- **Communicate by telephone and by regular mail**. Most family members do not have easy access to fax machines, e-mail, or Federal Express. If you request information from families (e.g. registration materials, speaker needs), make sure to allow ample time for families to respond by regular mail or give them your Federal Express number.
- **Think of every single thing that could go wrong and plan for it**. Always anticipate that some last minute changes will be part of the experience. Remember that families depend on your support and flexibility to participate.

BE AWARE OF PARENTAL BURN OUT

Most families are eager to participate in leadership and advisory roles. Their commitment to improving the system of care is deep; their willingness to participate in advisory activities seemingly endless. However, families, like professionals, can experience "burn-out." In fact, families, whose passion for the work developed from personal experience, may be at even greater risk for burn-out and exhaustion.

> "Parents involved in systems change . . .are asked to play both [public and private] roles simultaneously. They are asked to be their public selves, following the usual expectations for people who sit on boards and participate in meetings, while also drawing upon the deepest emotional experiences of their private selves and family life." (Gilkerson, 1994, p. 23)

Consideration must be given to supporting families in balancing the demands of their personal lives and the expectations of their roles as advisors. Innovative, flexible structures can be developed to protect families from becoming over extended.

- Project Uptown is a family support network for families from the many varied cultural and ethnic groups in urban Detroit. The Director position is shared by two parents of children with special needs, who bring different skills and experiences to the position. Job sharing also enables them to balance the demands of their children's care with work responsibilities.

Just as workshops and other training opportunities exist for professionals, so, too, should educational opportunities be offered to families to help in acquiring new skills. These kind of "perks" enable parents to enhance their abilities and replenish their energy, and also demonstrate that the program values the parents' contributions.

- The Cambridge Housing Authority hired families from several housing developments to help other families access the services they needed in the community. The paraprofessional family members received training in "Developing Helping Relationships" and earned college credit through the University of Massachusetts. This coursework increased the families' skills on the job and demonstrated the program's investment in their growth as paraprofessionals.

Families of children with special needs are a significant source of support to each other. Therefore, it is essential that families in advisory roles have opportunities to network with others in similar positions. Committees should always

Tips from the field

Judy Quest, the parent coordinator for Part H in Nebraska, convenes a conference call with the family representatives prior to each meeting of the ICC. She goes over the agenda, answers questions, and helps families verbalize concerns and formulate their questions. When families are not able to participate in the meetings because of illness or just needing a break, they are still included in the phone calls so they can continue to feel a part of things. Judy even puts calls through to the hospital bedside when a family has a child in the hospital and still wants to stay involved.

Tips from the field

Linda Gilkerson, of the Erikson Institute in Chicago, stresses that supportive structures and processes should be developed for parents in leadership positions. Among the ideas she recommends in *Zero to Three* are:

- Providing compensation for parent services.
- Establishing a "parental leave" policy for boards, committees and task forces to allow families to take a break when other demands are paramount.
- Exploring shared leadership models, such as co-chairing committees with another parent or with a professional.
- Providing clerical support and office space for parents.
- Encouraging parents to set boundaries around their availability to providers and to other families.
- Providing peer and professional consultation and mentoring to parents around leadership skills, group dynamics, and strategic planning.
- Ensuring opportunities for parents in leadership roles to network and gain support from other parents in similar positions.

include several family members, so that there is a built-in peer group for families. Peer mentors should be made available to families who are new to advisory activities. Parents should be linked to local, state, and national parent and family support and information groups to increase their network of parent leaders. Finally, families should be supported in participating in state and national parent-to-parent conferences, where they can have opportunities to meet with and learn from other families in leadership roles.

- The Federation for Children with Special Needs CAPP National Parent Resource Center was established to strengthen family participation in health policy and program development. One of CAPP's roles is to provide training and support to family members who are in leadership positions in their states and nationally. The group of CAPP Resource Parents meets annually to build their skills, share resources, develop position papers, renew themselves, and share frustrations and successes.

BELIEVE FAMILY PARTICIPATION IS ESSENTIAL

The single most important guideline for involving families in advisory roles is to believe that their participation is essential to the design and delivery of optimum care and services. Without sustained family participation in all aspects of policy and program development and evaluation, the care system will fail to respond to the real needs and concerns of those it is intended to serve. Effective family/provider partnerships are the mechanism for shaping a service system that is humane, efficient, and cost-effective. Once providers embrace this principle, they can successfully negotiate the challenges to family involvement at the policy and program level. They will also discover a more gratifying, creative, and invigorating way to practice.

The tool, "Families as Advisors: A Checklist for Attitudes" can be used to assess one's own attitudes and beliefs about family participation in advisory activities.

FAMILIES AS ADVISORS: A CHECKLIST FOR ATTITUDES

- Do I believe that parents bring unique expertise to our relationship?
- Do I believe in the importance of family participation in decision making at the program and policy level?
- Do I believe that parents' perspectives and opinions are as important as professionals'?
- Do I believe that families bring a critical element to the team that no one else can provide?
- Do I consistently let others know that I value the insights of families?
- Do I work to create an environment in which families feel supported and comfortable enough to speak freely?
- Do I listen respectfully to the opinions of family members?
- Do I believe that family members can look beyond their own child's and family's experiences?
- Do I clearly state what is required and expected of families in their advisory roles?
- Do I help parents set clear goals for their role?
- Do I understand that a child's illness or other family demands may require parents to take time off from advisory responsibilities?
- Do I feel comfortable delegating responsibility to families?

Families in Advisory Roles: Parent Consultants and Parent Advisory Councils

Examples of the many creative and varied ways that families are working in collaboration with providers at the policy and program level have been presented throughout this publication. The final section of *Essential Allies* focuses on two of the most well-developed approaches to ensuring family involvement in shaping care and services. The first is the development of paid staff positions for parents, sometimes called Parent Consultant or Parent Liaison positions. The second is Parent Advisory Councils, formal committees that provide regular input on policy and program issues.

PARENT CONSULTANTS

The parent consultant is a unique member of the hospital staff who shares the parents' perspective of having had a chronically ill child. That bond, along with their institutionalized role and responsibilities, enables them to help the family in a way in which no one else is likely to be able.

Benson, Forman, Pitel, Pitel, Prince, & Richards, 1985

The number of programs employing family members as paid staff has increased over the last two decades. So, too, have the responsibilities assumed by families in these roles. Parent consultant positions initially evolved from an appreciation of the unique role that families play in providing support to each other. Hospitals and other institutions serving children with special health and education needs have hired parents to ensure that the families they serve have access to peer support.

- The pediatric oncology department at Rhode Island Hospital (now Hasbro Children's Hospital) first hired a parent consultant in 1975. Her role is to provide support and advocacy for families throughout the treatment process, and to serve as a liaison between the staff and families. The parent consultant also has responsibility for developing and implementing programs concerning childhood cancer and its impact on families, schools, and the community.
- Since 1979, the Special Education Parent Facilitators Program of the San Diego Unified School District has hired parents of children in the special education program to support other parents who are new to the system. The Parent Facilitators meet with newer parents or talk with them on the phone, answer questions, invite them to support groups, or help them negotiate the IEP process.
- In 1988, Phoenix Children's Hospital hired a full time Family Support Coordinator for the hospital. She is responsible for family support and information activities and takes an active role in teaching students and practicing professionals about family perspectives on the health care experience. In 1989 a second Family Support Coordinator who is bilingual was hired to increase support to Spanish-speaking families served by the hospital.

- The Children's Pediatric AIDS Program in Ft. Lauderdale hired the caregiving grandmother of a child who died of AIDS to provide support to families receiving services through the program. As the program's Family Consultant, she coordinates the activities of the family-to-family support network, manages a clothing closet for families, participates in staff and policy meetings, and visits families at home, bringing food and supplies. On clinic days, she greets families as they arrive and provides information, support, and encouragement.
- In the Transitional Care Program at Children's Hospital of St. Paul, a Parent Consultant helps families of children with complex medical needs make the transition to home and the community. She meets with families to provide support and resources, assists families in developing partnerships with providers, and works with home health agency staff to assist them in working more effectively with families.

Over time, parent consultants' roles have expanded to include policy and program development and evaluation. For example, twenty-one Title V Children with Special Health Care Needs programs now employ families as paid staff (CAPP National Parent Resource Center, 1993). As program administrators have realized the tremendous value of incorporating family perspectives at every stage of program and policy development, they have broadened the scope of the parent consultants' responsibilities.

- The Children With Special Health Care Services (CSHCS) program in the Michigan Department of Public Health has developed a comprehensive approach for ensuring the involvement of families as consultants and advisors in their programs. In 1988 the department hired the parent of a child with special health needs to coordinate the Parent Participation Program. This program has two major goals: 1) to provide parent and family input to CSHCS administration regarding programs and policies at the state, county, and local levels; and 2) to develop a statewide network of parent-to-parent support for families of children with special needs. The Program Coordinator is an integral member of the department's administrative team, participating in all policy development and authorization activities as well as interviewing and hiring professional staff. She also administers the Family Support Network, which is comprised of 110 Volunteer Local Family Support Network Coordinators, and more than 600 trained volunteer Support Parents who provide support, information, and resources to families throughout the state.

Tips from the field

Bev McConnell, the director of the Parent Participation Program of the Michigan Department of Public Health, and Helena Richards, formerly the Parent Consultant for the Pediatric Oncology Department at Hasbro Children's Hospital, agree that three things are required to successfully establish a Parent Consultant position.

- There must be vision and commitment to family/professional collaboration on the part of the top level administration.
- The parent must be willing to take risks in this new role.
- The parent must have experience with and connections to other parent support and information groups in the community.

- The state of Florida has hired two Parent Consultants, one to work with Children's Medical Services and one to work with Part H. These Parent Consultants provide consultation and technical assistance to staff statewide to ensure that programs and services for infants, toddlers, and children with special health care needs and their families adhere to family-centered principles. In addition, they are responsible for evaluation activities that measure family satisfaction with services. The Parent Consultants also provide training and support to a network of Regional Resource Parents throughout the state.

Having parents in paid staff positions demands flexibility and change on the part of providers and organizations. Unique challenges may arise as these new staff positions are integrated into existing administrative structures. For example, what qualities should a program be seeking in a parent? How does a program identify parents for these positions? Is special training required? How should job descriptions be developed? How is the parent's performance to be evaluated? Who is the best person to provide supervision?

The Hiring Process. Because parent consultant positions require skills that are not easily conveyed in a traditional resume, innovative processes for identifying and interviewing candidates for these positions are necessary.

- The Parent Leadership Program of the Association for Retarded Citizens (ARC) in Michigan has developed an innovative approach to recruiting and interviewing parents of children with special needs for staff positions. They seek individuals with collaboration, leadership, and organizational skills who demonstrate enthusiasm, flexibility, and excellent interpersonal skills. Because many family members, especially those who do not have formal training, minimize their abilities, PLP developed a nontraditional approach for identifying candidates. Initially applicants receive the job description, the required travel schedule, and an essay-type questionnaire designed to capture applicant's abilities, perceptions, and values. Candidates are selected for an interview based on their questionnaire responses. Since the position requires training, interviewed applicants are also asked to generate a 10 minute presentation on a subject of their choice. While this recruitment and selection process requires a lot of effort, PLP believes it results in the selection of highly qualified parents whose skills match the needs of the program.

The complete packet developed by the Parent Leadership Program for recruiting, interviewing, and hiring parents for staff positions is presented in the appendix.

Tips from the field

The insights and resources that families already serving in paid positions can share provide important guidance for overcoming the common challenges of developing Parent Consultant positions. At the annual Association of Maternal and Child Health Programs meeting in 1994, family members employed in Title V programs and other professionals from these agencies met to discuss and develop recommendations on hiring, job descriptions, role expectations, and preparation and training for parents in these roles. A report of this meeting is available from the Federation for Children with Special Needs in Boston.

Job Descriptions. Meaningful job descriptions that clearly and carefully present the job expectations and responsibilities of the parent consultant are also essential to success. All too often, families are hired without a job description or even a clearly designated area of responsibility. This lack of role definition and expectations can lead to confusion and disappointment. Administrators, staff, and families must have a shared understanding of the parent consultant's role.

Below is a sample job description for a Parent Consultant position in a community-based early intervention program. Examples of job descriptions for Parent Consultant positions in other settings are presented in the appendix.

SAMPLE JOB DESCRIPTION

PARENT CONSULTANT FOR EARLY INTERVENTION PROGRAM

Duties and Responsibilities:

- Organizes, implements, and provides leadership for the Parent Support Network.
- Chairs the Parent Policy Committee, convenes meetings, disseminates information and resources to families prior to the meeting, and develops and prepares materials for families.
- Provides direct support for families.
- Develops and conducts a family satisfaction survey.
- Develops and maintains link with other agencies, parent organizations and support groups, and other providers.
- Develops a family resource library.
- Develops a quarterly newsletter for families.
- Provides training for staff and families on family-centered care and family issues, and other issues of interest.
- Assists in evaluation of program activities.

Qualifications:

- Parent or family member of child with special needs.
- Strong interpersonal skills.
- Experience interacting with other parents of children with special needs.
- Working knowledge of committees and organizations.
- Familiarity with informal peer support.
- Knowledge of family-centered care.

Supervision. Organizations hiring parents for paid positions must be sure to establish a strong and supportive supervisory relationship for their new employees. Parents in these positions stress the importance of an accessible, knowledgeable supervisor as essential to their success in navigating these new roles. Often parents have been hired for positions for which they have not had complete training. Sometimes they must "prove" themselves to co-workers who question their abilities. At times they may be confronted by system barriers that are frustrating or illogical. They may need help in understanding the "culture" of the organization. These are some of the very real workplace challenges that families confront when they assume a paid staff position. Ample time and opportunities must be provided for parent consultants and their supervisors to address these issues as they arise. Open and honest communication between the parent consultant and the supervisor are fundamental requirements to the success of this pioneering work.

Tips from the field

Brunilda Torres, Director of Family and Community Support, CSHCN, for the Massachusetts Department of Public Health and Katie Bond, the parent consultant for MassCARE, the statewide system of care for children with HIV infection in Massachusetts, work together to develop and refine Katie's job description over time. This "process" approach to defining Katie's role enables them to create a position that is responsive to the unique needs of the families served by the program.

The tool, "Parents in Paid Positions: Common Challenges — Effective Solutions" presents some of the issues that may arise as parents assume paid consultant positions and some strategies for dealing with these concerns. It is important to remember, however, that even when all the suggested strategies have been brought to bear, there may still be difficulties or conflicts as providers and parents develop these new relationships. Seeking outside consultation or learning some conflict management skills may be required. Some struggle is inevitable as new ground is forged. It is a healthy reflection of growth and change.

PARENTS IN PAID POSITIONS: COMMON CHALLENGES — EFFECTIVE SOLUTIONS

Challenge: Parents are experts as parents but may initially lack the professional skills needed to work in an organization. They may be asked to do things for which they have not had complete training.

- Clearly articulate role expectations.
- Develop clear job descriptions.
- Create opportunities for families to learn new skills.
- Ensure access to supervision.
- Establish a mentoring program for families.

Challenge: A family member may be hired because of outstanding interpersonal skills, but lack the administrative skills needed for the job.

- Create a range of parent involvement positions.
- Hire those with "parent" skills as well as traditional professional skills to do administrative work.
- Create opportunities for families without formal education to do community outreach and public speaking.
- Provide training to families.

Challenge: Parents of children with special needs may have extraordinary caregiving needs. How can those family needs be balanced with the needs of a job that must get done?

- Develop part time positions.
- Offer job-sharing.
- Reimburse for phone calls made from home.
- Develop flexible hours and flexible work places.
- Develop a parent sabbatical or parent leave policy.
- Assist families in establishing boundaries between work and home.

Challenge: Professionals may resist or be unsure how to begin working with families.

- Demonstrate strong administrative support.
- Provide inservice opportunities for professionals — present both theoretical and practical aspects of family involvement and family professional collaboration.
- Develop training opportunities for families and providers together.
- Help providers see the advantages for themselves and for the program.
- Keep providers informed of the work the parent is doing.
- Keep saying families are the experts.

The most successful parent advisory committees are those with a clear sense of who is asking for advice, what advise is being sought, and who is committed to hearing and responding to the advice.

B. Schwab, 1992

PARENT ADVISORY COUNCILS

Parent Advisory Councils are an effective and widely used method for ensuring family involvement in policy and program development. Hospitals, state agencies, and community-based organizations have developed these policy bodies to provide input and oversight to their organizations. Ninety-eight percent of state Maternal and Child Health/Children with Special Health Care Needs Programs have Parent Advisory Committees or task forces (CAPP National Parent Resource Center, 1993). By law, each state Part H program must have an Interagency Coordinating Committee, of which 20% must be parents. Dozens of hospitals in the United States have formed parent advisory and parent/professional committees and boards.

- The Parent Advisory Council of Phoenix Children's Hospital was established in 1985 to facilitate family/professional collaboration on issues that are of concern to families of hospitalized children. The council plays a significant role in program and policy development, and was instrumental in the creation of Family Support Coordinator positions in the hospital. In addition, the council is involved in staff education, future planning for the hospital, quality improvement initiatives, and public relations and community involvement.

- The Title V program in Louisiana established a statewide family/professional advisory board. Fifty percent of the members are parents of children with special health care needs. A parent, who is a recipient of Title V services, and a physician co-chair the advisory board. Each regional office in the state nominated parents and professionals from their area to serve on the advisory board. The board meets quarterly in a clinic centrally located in the state. As part of their initial orientation, board members toured the clinics and met with staff and parents throughout the state to learn about their concerns and needs.

Parent Advisory Councils serve many functions in organizations. They can be formed as part of a new initiative such as a construction or renovation project or developed as part of an organization-wide effort to implement family-centered care. Sometimes Parent Advisory Councils evolve into parent/professional advisory groups. Whatever form these councils take, they provide an excellent mechanism for involving families in policy and program decision making.

When considering a Parent Advisory Council, an organization should ask the following questions:

- Who wants the group and why?
- What will be the purpose of the group?
- Would a Parent Advisory Council be successful in our institution?

Councils are generally effective if the organization has demonstrated a commitment to providing family-centered care and if the council has real authority, reporting to top level administration and decision-makers. Parent Advisory Councils are successful if there is a sincere commitment from parents as well as the institution to devote the time, energy, and resources to the development of the group. "Family Advisory Councils: A Checklist for Getting Started" lists strategies and steps for initiating an advisory council in any organization.

Sample documents such as Council by-laws, membership recruitment strategies, and guidelines for developing agendas are presented in the appendix. These materials can help guide organizations in the development of Parent Advisory Councils.

FAMILY ADVISORY COUNCILS: SOME OF THE ADVANTAGES

- Provides an effective mechanism for receiving consumer input.
- Results in more efficient planning to ensure that services meet family needs.
- Leads to increased understanding and cooperation between families and staff.
- Promotes respectful, effective partnerships between families and professionals.
- Offers a forum for developing creative, cost-effective solutions to problems and challenges faced by the program.
- Supplies a link between the program, its surrounding community, and community groups.
- Provides increased emotional support and access to information for families.

FAMILY ADVISORY COUNCILS: A CHECKLIST FOR GETTING STARTED

- Read the available literature.
- Talk with people who have been involved in advisory groups in other organizations.
- Convene a planning meeting with a small group of family members committed to implementing an advisory council. This can be initiated by either a parent or a provider.
- Develop specific goals.
- Conceptualize the structure of the group.
- Define potential benefits and risks.
- Contact the leadership of your organization by letter to request a meeting with administrative personnel. Follow up with a phone call.
- Present a convincing case for consumer involvement to your organization. Anticipate questions and provide written materials on other advisory groups. Include telephone numbers of people to contact in other organizations with advisory councils.
- Ask for general administrative support as well as help with specific needs.
- Request a staff person be assigned as liaison to the committee. This person must:
  - have authority
  - have a commitment to family-centered care
  - be able to work closely with families
  - have access to support staff
  - have time to devote to the committee
- Obtain a commitment of funds for supplies, copying, postage, and refreshments for meetings.
- Obtain a commitment for meeting space.
- Communicate the existence of the group through announcements at staff meetings, articles in employee newsletters, announcements on bulletin boards, and in materials for families served by the organization.
- Develop by-laws.

(adapted from Phoenix Children's Hospital materials)

In Conclusion

Professionals need to become allies of the family. There is power in that alliance.

M. Beyer, 1993

Essential Allies: Families as Advisors has presented many ways that families are contributing to the development of a more compassionate and effective service system for children and families. Family involvement in shaping policies, programs, and practices is resulting in improved care and services as well as increased satisfaction among the recipients of those services. Their participation is redefining relationships between professionals and families and forging opportunities for real change in the way care and services are planned, delivered, and evaluated. The "Checklist for Involving Family as Advisors and Consultants" summarizes the principles that have been presented in this publication. It can be used to assess a program's or organization's current approaches to involving families as advisors as well as to plan for their future participation.

By maintaining a broad vision of collaboration and being vigilant about opportunities for family involvement in policy and program planning and decision-making, professionals can continue to build on the national momentum for family-centered change and ensure that the service system is responsive, effective, cost efficient and humane.

Checklist for Involving Families as Advisors and Consultants

This checklist is a tool to help think about ways that families are participating as advisors and consultants at the policy and program level. Rate each item and then cite specific examples that illustrate how the program is involving families. Use this tool to initiate new opportunities to work in partnership with families or to expand on current activities.

	We're not doing well	We're doing okay	We're doing very well	Examples
■ We recognize and respect the expertise of families as policy and program advisors.				
■ We are vigilant about seeking opportunities to involve families in advisory activities.				
■ We seek to involve families who reflect the racial, ethnic, cultural, and socioeconomic diversity of families *currently* served by the program.				
■ We seek to involve families who reflect the racial, ethnic, cultural, and socioeconomic diversity of families in the broader community and region.				
■ We use a variety of strategies to identify and recruit families to serve in advisory roles.				
■ We demonstrate appreciation for the contributions that families make to policy and program development.				
■ We have developed both short term and long term advisory roles for families.				
■ We create opportunities for families to participate that are consistent with their cultural practices and individual personalities.				

	We're not doing well	We're doing okay	We're doing very well	Examples
■ We have developed a range of ways for families to participate as advisors including: - participating as trainers in staff orientation and inservice programs - reviewing written and audiovisual materials developed by the program - conducting evaluation activities - participating in focus groups - serving as members of committees, boards, and task forces - reviewing grants - developing educational and informational materials for other families - conducting needs assessments				
■ We support families serving in advisory roles by: - reimbursing their travel and child care expenses - offering a stipend or honorarium for their participation - providing mentors - offering training programs and workshops - providing secretarial support - facilitating their networking with other families - being aware of parental burn out				
■ We provide training to staff on working collaboratively with families at the policy and program level.				
■ We have a paid Parent Consultant(s) on staff.				
■ We support the Parent Consultants by: - creating flexible work schedules - developing clear job descriptions - ensuring access to a supportive supervisory relationship				
■ We have a Family Advisory Council or committee.				
■ Membership on the Advisory Council reflects the diversity of families served by the program.				
■ The Family Advisory Council reports to top level administration.				

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Sample Job Descriptions

The following samples serve as useful starting points for developing job descriptions that reflect the needs of the job as well as the strengths of the parent advisor or consultant. Job descriptions should be developed and refined over time with the parent advisor as skills and responsibilities develop and change. Included are job descriptions for parent consultants in a variety of settings: a pediatric hospital's oncology department, a staff position for a state interagency coordinating council, and a grant funded project in a state health department.

JOB DESCRIPTION: PARENT CONSULTANT

Adapted from Rhode Island Hospital, Providence, Rhode Island

GENERAL SUMMARY

Reports to the Director of Pediatric Hematology/Oncology. Serves as a liaison and advocate for families of children with cancer. Provides counseling and support to families through the entire treatment cycle: inpatient, outpatient, home care, death and bereavement. Plans and conducts internal/external workshops, educational sessions, and lectures to educate families, other hospital professionals, and others within the community about the stresses of dealing with cancer in children. Functions as a member of an interdisciplinary team providing diagnostic and treatment services to children with cancer.

DUTIES AND RESPONSIBILITIES

1. Provides counseling, education, and support to families of children diagnosed with cancer, to help them cope with stress of treatment cycle: including inpatient, outpatient, home care, death and bereavement. Participates in developing related policies and procedures.
2. Functions as a member of an interdisciplinary team as the family/child advocate and liaison. Presents evaluation of needs as gathered through interviews, medical records, observations and conversations, to assist other professionals in overall treatment plan.
3. Plans and conducts workshops, educational sessions, and presentations to families, other professionals within the hospital, and others in the community to educate on needs and stresses of dealing with cancer in children. Provides insight on helping the child/family function and shares patient/parent perspectives.
4. Identifies problems in hospital services through interviews of staff and parents, and acting as patient/parent advocate, recommends solutions to appropriate departments to resolve problems, such as shortening waiting time in clinic, prioritizing delivery of services, expediting parking, billing problems, etc.
5. Serves as Parent Consultant on hospital committees such as Pediatric Oncology Planning and Ad Hoc Committee for optimum care of terminally ill patients. Acts as facilitator for parent self-help groups, including Parents Allied to Help, Bereaved Parents' Group, mothers' groups, etc. Represents the Hospital by attending and participating in various professional organizations, such as American Cancer Society, and the Leukemia Society of America.

6. Participates with other team members in writing grant proposals to obtain funding for additional services.

7. As requested by the Director, may participate in interviewing other Pediatric Oncology professionals applying for positions.

8. May develop educational material or prepare papers for publication, such as Parent's Handbook on Leukemia, as distributed by American Cancer Society.

9. Maintains and enhances professional expertise through appropriate educational activities.

SKILLS AND ABILITIES

1. High level of interpersonal skills to function as a member of interdisciplinary professional team, and to effectively interact with patients, families, and others within and outside the hospital.

2. Oral and written communication skills to develop and present workshops, educational sessions and lectures and to prepare papers for publication.

3. Ability to provide psychosocial support to families and children with cancer from time of diagnosis through death and bereavement.

WORKING CONDITIONS

1. Patient care area with risk of exposure to communicable diseases.

2. Some travel to make home visits to patients and families and to attend and participate in various meetings.

MINIMUM LEVEL OF PREPARATION AND TRAINING

1. Bachelor's Degree in Social Work or the equivalent in life or work experience, with courses preferred in child development, stages of dying and grief.

2. One or two years on-the-job experience providing counseling, education, and support to parents of terminally ill children.

3. Life experiences as parent of child with cancer.

FAMILY PARTNER POSITION

Job Activities

Adapted from Nebraska Interagency Coordinating Council

- Available to represent families as a well informed participant whenever issues concerning families of young children with disabilities are being discussed.
- Is a partner to state and local professionals. Participates in joint speaking engagements, drafting of procedures, and providing input on service delivery models.
- Works in close collaboration with the parents on the Nebraska Interagency Coordinating Council in state efforts to advance the priorities of families.
- Works with parents who serve on local interagency coordinating councils to help strengthen their positions with training, networking and resource awareness. Represents their concerns and issues at state level meetings.
- Is in constant contact with other parent organizations in the state and nationally to collaborate efforts and support the common agendas.
- Available to planning regions to assist them in their work with families.
- Works with others on the development of materials for parents on topics such as family-centeredness, the IFSP process, and Nebraska's services for families having a child with a disability.
- Promotes and explains concepts such as IFSP process, family systems, family-centeredness, and collaboration.
- Keeps current on legislation and best practice regarding services for families having young children with disabilities.
- Works in close collaboration with families and other team members to promote the serving of children and families who are underserved.
- Maintains a sense of humor, a sense of vision, and a positive attitude!

FAMILY PARTNER POSITION

Qualities, Skills, and Abilities

Adapted from Nebraska Interagency Coordinating Council

■ COMMUNICATIONS

Listening: Ability to actively listen to parents and people involved in service delivery at every level.

Oral Communications: Ability to effectively express oneself to individuals or groups.

Oral Presentation: Ability to present ideas to individuals or groups; public speaking.

Written Communication: Ability to express ideas in writing and in good grammatical form.

Technical Translation: Ability to convert laws and professional jargon into layman's language for parents.

■ PERSONAL

Integrity: Ability to maintain ethical and organizational standards. Ability to keep parent concerns as primary while respecting system concerns.

Practical Learning: Ability to keep up on information in the field such as new approaches to family-centered services as well as family concerns and legislation affecting families.

Initiative: Ability to actively attempt to influence events, to achieve goals, to be self-starting rather than passively accepting. Ability to take action to achieve goals and originate action beyond what is necessarily called for.

Confidentiality: Ability to maintain respect for privacy.

Creativity: Ability to generate new ideas and seek innovative solutions for problems.

■ MOTIVATIONAL

Work Standards: Ability to set high goals of performance for self, others, and the organization.

Vision: Ability to see the big picture and strive for ideals.

Family Partner Position (cont'd)

Professional Interest: Desire to actively pursue information in the areas of families, disabilities, and services. A constant striving to get to know the concerns of all families.

Independence: Ability to work alone and without constant direction.

■ INTERPERSONAL

Impact: Ability to create a good first impression, command attention and respect, show an air of confidence.

Rapport-Building: Ability to meet people easily and to be liked; to get along well with people of different positions and backgrounds and put them at ease.

Sensitivity: Ability to be considerate for the feelings and needs of others. → Sensitivity to cultural diversity, family systems, and socio-economic differences.

Leadership: Ability to use appropriate interpersonal styles and methods in guiding individuals or groups toward task accomplishment. Ability to build up skills in others (parents or team members).

Flexibility: Ability to modify behavior according to needs.

Negotiation: Ability to communicate a position well and respectfully consider other positions in order to come to a mutual decision. Ability to work as an effective team member.

Tenacity: Ability to stay with a position or plan of action until the desired objective is achieved or is no longer reasonably attainable.

Adaptability: Ability to maintain effectiveness in varying environments, tasks, or responsibilities.

Independence: Ability to work and act self-sufficiently.

■ MANAGEMENT

Planning and Organization: Ability to establish a course of action to achieve a goal. Ability to allocate time and other resources effectively and efficiently.

■ SELF-DEVELOPMENT

Self-development orientation: Initiates actions to improve skills and performance proficiency. Shows active efforts toward self-development.

FAMILY SPECIALIST POSITION

Adapted from Health Research, Inc. announcement of job vacancy at Family-Professional Training Institute

TITLE	Family Specialist for the Family-Professional Training Institute
GRADE	G-16
LOCATION	Bureau of Child and Adolescent Health, New York State
MINIMUM QUALIFICATIONS	Parent of child with special health care needs. Experience in assisting other parents whose children have special needs. Knowledgeable about service delivery systems, including health, education, and social services. Experience in speaking before an audience and planning meetings. Excellent communication and writing skills.
PREFERRED	Bachelor's degree, preferably in the field of nursing, social work, education, health education, psychology, and other relevant fields, or certification in child life, or four years experience working with families whose children have special health care needs. Prospective candidate should be able to demonstrate a working knowledge of issues for families who have children with special health care needs and of issues that relate to collaboration with professional. Participation in training programs for families whose children have special health care needs.
RESPONSIBILITIES	Maintain communication and linkages with families or children with special health care needs to provide support, exchange information, and obtain input on program actions. Review and evaluate information from families and professionals to determine possible courses of action that may improve service delivery systems. Prepare written reports. Organize meetings, speak before groups of parents and professionals. Provide assistance to the project director in the development, delivery, and evaluation of activities. Travel required.

Materials for Recruiting & Selecting Families for Staff Positions

The following materials were developed by the Parent Leadership Program of the Association of Retarded Citizens (ARC) Michigan to facilitate the selection and hiring of parents for paid positions. The sample documents in this recruitment packet can be used to develop a comprehensive process to identify and select parents to serve in advisory roles for a variety of settings. Included are the position description, the applicant questionnaire, sample letters to applicants, and personal interview questions.

Adapted from Parent Leadership Program position description

EARLY ON is Michigan's comprehensive, interagency, family-centered system of early intervention services for infants and toddlers who have been diagnosed as having an established condition or a developmental delay. The Parent Leadership Program was developed to provide families with training and opportunities to assist them in their involvement in EARLY ON.

Currently, there is an opening for a PLP staff position. All applicants must be a past or current primary caregiver of a child with special needs.

QUALIFICATIONS

1. Willingness to develop skills as a trainer.
2. Strong interpersonal skills, including the ability to actively listen.
3. Ability to organize and share ideas with families who have a variety of backgrounds and experiences.
4. Creative problem-solver.
5. Able to prioritize.
6. Has had the experience of being a participant as a member of a group.
7. Self-motivated.
8. Past work or volunteer experience.
9. Willing to work independently.

RESPONSIBILITIES/JOB DUTIES

Serve as a member of the team. Coordinate efforts with support staff. State-wide travel is required.

1. Assist with organization and facilitation of training days.
2. Represent PLP on various state level committees.
3. Provide support and encouragement to PLP's participants/family delegates.
4. Assist with other PLP duties as assigned.
5. Provide feedback on written materials.
6. Actively participate in workshops/presentations and conferences.
7. Provide support and encouragement to regional family field consultants.
8. Regularly attend staff and advisory team meetings.
9. Submit required reports on time.

SAMPLE LETTER TO APPLICANTS

Adapted from Parent Leadership Program

January 30, 1991

Cathy Jones
20 Main St.
Anytown, USA 00000

Dear Ms. Jones,

We are very pleased that you are interested in applying for PLP's new staff position. Enclosed you will find three important items.

1. The job description.
2. The required travel schedule
3. The applicant questionnaire

After reading the materials, please fill out the questionnaire. Be sure to staple a cover sheet with your name and address to the questionnaire. We do not want this to get separated and lost. The questionnaire is due back by February 28.

Please do not send resumes. The selection process for interviews will be based solely on your responses to the questions. If you are selected for an interview you will be contacted by Joanne Smith.

If you have further questions or concerns about the application process, please contact Joanne.

Sincerely,

Bob Nelson
Project Director

APPLICANT QUESTIONNAIRE

Adapted from Parent Leadership Program

Please answer the following questions. Feel free to use extra paper if needed.

1. If you have had previous work or volunteer experiences, please describe your responsibilities and the skills you developed there. Please include these even if they were many years ago. How would any of these skills help you in this job?
2. What do you consider to be your personal strengths that would be useful in this job? Please describe how they could be applied to this job.
3. Why are you interested in applying for this job?
4. How would you handle this situation?
   You have a number of assigned work tasks due within two weeks. Your child is experiencing a new school situation that is not going well. Your time and attention are needed to resolve this issue at the school. What would you do and how would you proceed?
5. You find yourself in a committee with 20 professionals from various backgrounds. You are the only member representing the experiences of families who have children with special needs. The issue being discussed at this meeting is one you know well. Last week your family dealt with this same problem in your community. The whole experience left you feeling very frustrated and angry. You have an idea for a solution. But when you discussed it at a recent family support group meeting, many of those families did not agree with your ideas. What would you do in this situation?
6. When you are in group settings what type of role do you generally play? For example, quiet observer? Most outspoken? How do you think other group members feel about your input?
7. Your child's reading consultant recommended a new teaching plan. Although you do not have much information about this plan you have some concerns based on the fact that your friend's child had attempted it and failed. How do you approach this situation?
8. You have been "warned" by many different people that a particular family is very difficult to work with. There is a new project you are working on that requires you to interact with this family. How do you approach this situation?

SAMPLE INTERVIEW LETTER

Adapted from Parent Leadership Program

November 11, 1992

Jane Doe
10 Central Court
Anytown, USA 00000

Dear Ms. Doe,

Thank you for applying to the Parent Leadership Program. Enclosed is a map to our office. Your interview time has been scheduled for December 5 at 3:00 pm.

As a reminder, our interview team will consist of six participants. Please remember to prepare a ten minute presentation for the group on any topic you choose. If you have any audio-visual equipment needs for your presentation, please let me know.

We look forward to meeting you.

Sincerely,

Joanne Smith
Project Coordinator

INTERVIEW QUESTIONS

Adapted from Parent Leadership Program

1. Briefly, tell us about your family. What are some of the unique difficulties facing families who have children with special needs?
2. Define cooperation.
3. How would you define a conducive work atmosphere?
4. What would you do in a situation in which you disagree with your supervisor?
5. What kind of people do you like to work with? What kind do you find it difficult to work with? How have you successfully worked with this type person?
6. In what way is your approach to a challenge different from other people's?
7. Have you had any training experience? How do you feel about public speaking? Have you helped with any presentations or workshops?
8. Tell us about the last time you felt angry.
9. Describe a situation where your work or an idea was criticized.
10. What will be your biggest challenge if you should be offered this job? What interests you least about this job?

SAMPLE REGRET LETTER

Adapted from Parent Leadership Program

September 25, 1994

John Doe
20 Main Street
Anytown, USA 00000

Dear Mr. Doe,

Thank you for the time you spent with us recently while interviewing for our program staff position.

After careful consideration of your background and experience, we feel your qualifications are not close enough to the requirements of this position. Thus, we find ourselves unable to offer you a position at this time. However, I would like to keep your application on file for consideration should a more appropriate position become available.

Once again, thank you for your interest in the ARC Michigan's Parent Leadership Program. We wish you every success in finding a position that is meaningful to you.

Sincerely,

Joanne Smith
Project Coordinator

Developing Family Advisory Boards: Sample Documents

The following section offers sample documents that can be used in developing family advisory boards. Although these samples are for hospital advisory boards, the principles and techniques can be broadly applied to any advisory board that includes family members.

FAMILY ADVISORY BOARDS

Recruitment and Membership Suggestions

Adapted from Phoenix Children's Hospital Parent Advisory Council

1. Contact staff (physicians, administration, department heads) for names of parents who might be interested in serving on an advisory council. Attach a copy of bylaws and membership requirements to inform them of the purpose of the group.

2. Post notices throughout the hospital for parents, as well as staff, in a variety of areas (admitting, cafeteria, parent lounges, staff lounges, waiting areas, lobby) informing them of the group's existence and requesting recommendations.

3. Contact community groups and support groups, such as Pilot Parents, Cancer Society, Cerebral Palsy Association, etc., informing them of the existence of the group and requesting recommendations for members. Send bylaws and membership responsibilities to inform them of the purpose of the group.

4. As recommendations of individuals are made, contact each nominee with a letter and follow up with a telephone call to discuss the purpose and structure of the group. If they indicate an interest, invite them to an orientation session.

5. Remember that first meetings are very important. They set the stage for future interactions and therefore must be very well organized and positive. A comprehensive, well-planned, positive orientation is very important. The program should include:

    - Introduction of participants.
    - An overview of the facility and services. This is important as many parents have experience with only isolated areas or services.
    - A tour of the facility. Directors or other staff can direct the tour through their areas and highlight special services, etc. This can help members in later meetings visualize areas being discussed.
    - A number of brief presentations. Presenters should be top administrators and department heads to demonstrate their interest and commitment.
    - A review of bylaws, membership responsibilities and goals of the group.
    - Planned time either at the break or conclusion to allow members to socialize.

- Distribution of comprehensive packets of information to all attendees for them to take home to review. Include information regarding history of facility, structure, mission statement, etc.
- Provision of nice refreshments.

6. Plan the next meeting. At that time negotiate regular meeting time, location, nomination of officers, etc. Elect officers as soon as possible and shift responsibility to parents to conduct meetings. This creates a sense of ownership and responsibility and also will relieve anxiety about being "pawns of the institution."

7. Strive to select members that are representative of the total population, but recognize this is ideal and may not be achievable in the beginning. During initial recruitment, do not be too stringent regarding qualifications. Initially you may have a number of parents that represent the same specialty area. Make a special effort to recruit fathers and families from the diverse cultures served by the hospital.

8. When determining optimum size of the Council, keep in mind that smaller groups promote more intimacy and there is more pressure for people to participate. Larger groups sometimes create a tendency for a few people to do most of the talking while others seldom speak. However, also keep in mind that absenteeism is a potential problem, therefore, you may need a larger group to ensure enough manpower to accomplish tasks. We decided on a membership of 21, recognizing that parents of children with special needs may often have scheduling difficulties. This has worked well as there are always some absent members. On a consistent basis, approximately 12-15 parent members attend monthly meetings. This seems to be a good number to get needed input and accomplish stated goals.

9. After membership is formalized, develop membership roster with names and telephone numbers to distribute to all members.

FAMILY ADVISORY BOARDS GUIDELINES FOR MEETINGS

Adapted from Phoenix Children's Hospital Parent Advisory Council

- By group consensus, determine the following:

  Time: Decide on days or evenings. One solution is to hold day and evening meetings on alternate months (9:30 a.m. and 7:00 p.m.) Evening meetings increase the likelihood of attendance by working parents.

  Length: Allow enough time to cover agenda items, as well as some time for socialization. The informal support provided by the group is very important. Meetings of 1 1/2 hours are ideal. One hour is not long enough, however any longer than 1 1/2 hours increases the tendency to over-talk an issue and not use time productively. Make every effort to begin and end on time.

  Place: A neutral facility in a central location is ideal. A consistent meeting place facilitates group identity. Available parking is important. Keep in mind some parents may be sensitive about meeting in the actual hospital, particularly if they have painful memories such as the death of a child.

  Frequency: Monthly seems to be adequate. More frequently is too often for many parents. Less often allows too much time to lapse and not enough time to accomplish goals.

  Attendance: Develop a shared understanding of what is acceptable and expected.

- Locate a meeting room that is large enough to comfortably accommodate the group, but small enough to promote intimacy. A conference room located in an Outpatient Center might be ideal.

- It is important to provide refreshments. At morning meetings provide coffee, juice, muffins, donuts, and bagels. Coffee, soft drinks, and cookies can be provided at evening meetings.

- Consider providing child care services during meetings. If you cannot provide baby-sitting service, develop an informal understanding that bringing children is acceptable.

FAMILY ADVISORY BOARDS: DEVELOPING AGENDAS

Adapted from Phoenix Children's Hospital Parent Advisory Council

It is helpful if the agenda is developed jointly by the staff liaison and chairperson of the Advisory Council.

- Agendas should not have more than 5 or 6 items. More than that can be overwhelming and indicate a need for the group to meet more frequently. An exception to this may be if many items can be reviewed once, attended to, and then eliminated.
- Try not to spend longer than 10-15 minutes on any one item. If more time is needed, it should be assigned to a committee or an individual for further work and refinement.
- Discuss only one topic at a time. Frequently there is a temptation to go on to a related topic or "hotter" issue. If this occurs, the chairperson should get the group's consensus that this is a related topic or is more important than the topic being discussed.
- As much as possible, attempt to save items that may require lengthy discussion for later in the agenda. Discussing brief items that are easily resolvable early in the agenda increases the group's confidence that "We're really getting somewhere."
- Reinforce that group rules are to be followed by everyone. The Chairperson has a very important role and must model group rules by following them him/herself. For example, beginning and ending the meeting on time, following the agenda, and getting the group back on track when needed.
- It is very important that the chairperson model an open, positive, non-judgmental communication style.
- The chairperson must make an effort to draw out quieter members to help them become more assertive.
- The staff liaison must be supportive and act as a buffer.

HOSPITAL/FAMILY ADVISORY BOARD COMMUNICATION GUIDELINES

Adapted from Phoenix Children's Hospital Parent Advisory Council

1. It is crucial that there is on-going, open, two-way communication. Breakdowns in communication will result in misunderstandings, defensiveness, and intimidation.

2. Communication must be addressed on a variety of levels. These include:

   INTERNAL - Open discussion in meetings must be encouraged. Members need to be kept informed. If an individual misses a meeting, forward minutes and all information distributed at meetings.

   Encourage council secretary to take good, detailed minutes. Provide stamped, self-addressed envelopes to the secretary to mail her notes to be transcribed by staff.

   If members are to adequately represent the hospital, they must be kept informed about activities and issues. We share the following information on a routine basis:

   - Employee newsletters
   - Monthly Public Relations reports
   - Hospital newsletters
   - Conference brochures
   - Any other information relating to children's health, such as news articles, both in our hospital, our community, and nationwide.

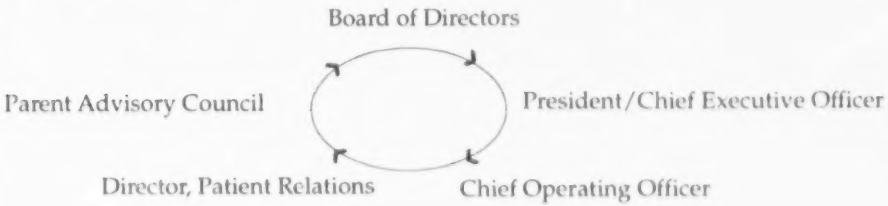
   IN HOUSE - Agendas, minutes and other information are posted on Parent Bulletin boards throughout the hospital and Outpatient Center. Also the following staff receive agendas of upcoming meetings and meeting minutes.

   - Chief Executive Officer
   - Chief Operating Officer
   - Associate Administrator/Director of Nursing
   - Outpatient Administrator
   - Director, Public Relations
   - Director, Volunteer Services
   - Critical Care Medical Director
   - ICN Medical Director
   - Chair, Medicine Committee

- Child Development Center Medical Director
- Nursing Managers of all patient care units
- Director, Child Life
- Director, Social Services

COMMUNITY - Circulate newsletters to other community support groups. Solicit attention from media.

3. A formal reporting structure can be established, however, it may not always be strictly followed:



4. Remember to always follow-up with thank you notes to individuals who attend meetings to give presentations.

5. The following is an example of an article which appeared in the employee newsletter:

Parents Speak Out for PCH

A Parent Advisory Council has been created to act as an advisory resource committee to the Administration of Phoenix Children's Hospital.

"The Council represents parents from all specialty areas," said Marcia N., Patient Relations Manager. "They are parents of children who are patients here, and they care about the future of the hospital."

Some of the responsibilities of the Council are: "To promote better understanding of the services and policies of our hospital among parents and to give us input regarding their needs and concerns," Marcia said.

"Parents have been extremely responsive and positive about the hospital. The Council is going to play an important role at PCH," she said.

Council meetings are held monthly at PCH Administration. For more information please call Marcia N. at _____

FAMILY ADVISORY COUNCIL BY-LAWS

Adapted from Hasbro Children's Hospital of Rhode Island Hospital

Article I **Name**

The name of the organization shall be Hasbro Children's Hospital Family Advisory Council (HCH FAC).

Article II **Mission**

The Family Advisory Council seeks to enhance the delivery of health care at Hasbro Children's Hospital by providing a vehicle of communication through cooperative efforts between the families and the entire staff.

Article III **Goals**

The goals of this Advisory Council shall be to:

- Provide a vital link between the Hasbro Children's Hospital and the community
- Provide supportive channels of communication between families and hospital staff
- Provide input and feedback on delivery of services for children and their families
- Review issues referred to the Family Advisory Council and provide recommendations
- Monitor, evaluate and address multi-cultural needs and issues of families
- Facilitate families in the forming, accessing and using of various support groups
- Provide input and participate in education of health care professionals and all other hospital personnel
- Educate families in health care issues
- Provide input regarding program development
- Assist in planning for new facilities and services
- Provide a liaison to "Friends of Hasbro Children's Hospital" and other fundraising groups

Article IV **FAC General Membership**

Section 1 Composition

The FAC General Membership shall consist of individuals who subscribe to the mission and goals of the FAC and are registered annually with the FAC Vice Chairperson.

Section 2 Duties

Each member shall attend FAC meetings and meetings of any committees on which they serve. Each member shall maintain active participation in general FAC meetings, activities, and committees.

Section 3 Meetings

A. The FAC shall adopt a schedule of regular meetings or may delegate the scheduling of such meetings to the Chairperson. All FAC members and HCH representatives shall be notified either by mail or telephone of any meetings.

B. Meetings shall be at the call of the Chairperson.

C. FAC meetings shall be open to anyone wishing to attend.

D. The Annual Meeting shall be held in May.

Section 4 Voting

FAC General Membership
Members shall be entitled to one (1) vote at the Annual Meeting to elect the FAC Board.

Article V FAC Board of Directors

Section 1 Composition

The members of the FAC Board of Directors shall be:

A. Parents, patients, or immediate family members who have experienced a pediatric hospitalization or ongoing pediatric outpatient treatment.

B. In order to achieve representation from the population served, there shall be parent representatives from a wide variety of pediatric specialties.

C. Members shall represent not only specific diagnoses but also the geographic areas and cultural diversity of the population served.

D. A member may represent more than one of the aforementioned groups.

E. The total FAC membership shall not exceed twenty one (21) voting members.

F. In addition, the Council Board membership shall consist of the following non-voting members or their designees:

- Executive Director of HCH
- Chief of Pediatrics
- Director of Pediatric Services

- Manager of Child Life
- Manager of Clinical Pediatric Social Work
- Coordinator of Pediatric Volunteers and Patient Representatives
- A Rhode Island Hospital Trustee

Section 2 Duties

A. The FAC Board shall be an advisory group reporting to HCH Administration.

B. The FAC Board shall develop an annual plan to include goals and objectives.

C. The Chairperson, with the assistance of FAC Board Members and HCH representatives, shall prepare regular progress reports describing the activities of the FAC and identifying matters which require FAC action. An annual evaluation and report on effectiveness of FAC activities shall also be prepared and distributed by the Chairperson at the Annual Meeting and distributed to the Management Team of HCH.

D. Minutes shall be kept of all FAC and committee meetings and shall be distributed to appropriate HCH personnel.

Section 3 Nominations and Elections

A. A Nominating Committee Chairperson shall be appointed by the chairperson of the Council in February of each year. An additional four (4) members shall be selected by the Executive Committee, based on recommendation from the General Membership. As far as possible, these members of the Nominating Committee shall be representative of HCH's patient population geographically and ideologically. The Nominating Committee shall solicit recommendations for the FAC Board from the FAC General Membership.

B. The duties of the Nominating Committee shall be to submit, on or before the first day of April of each year, a list of FAC members slated to fill each expired Board Member's term to the Secretary of the FAC.

C. Notification — The FAC secretary shall, within one week of receipt of the nominations for the FAC Board positions, cause the names of said nominees to be published in conjunction with the Annual Meeting notice.

D. Voting — Voting to fill expired terms shall take place at the Annual Meeting. The vote shall be done by ballot only when there is more than one candidate for each position. Each FAC Board member shall have one (1) vote. Board members shall be elected by a majority.

Section 4 Meetings

A. FAC Board meetings shall be scheduled and called in accordance with Article IV, Section 3.

B. FAC Board members shall notify the Vice Chairperson if they are unable to attend a FAC meeting or are unable to fulfill their commitment.

C. Voting — FAC Board members shall be given seven days prior notice of the issue and meeting at which said issues shall be voted upon. This provision may be waived by a two-thirds (2/3) vote of those FAC members present.

D. Quorum — The quorum of any meeting of the FAC Board shall be one third (1/3) of the membership of the FAC Board.

Section 5 Term of Service

The term of service of each elected member shall be two (2) years. All elected members shall serve until the successors have been elected and qualified. No FAC Board member shall serve for a period exceeding six (6) consecutive years.

Section 6 Vacancy of Position on the FAC Board

A vacancy in a FAC Board position shall be filled by the FAC Board.

Section 7 Removal from Position on the FAC Board

Any elected or appointed member of the FAC Board may be removed at any time by the FAC if, in the judgment of the FAC, such removal shall be in the best interest of the FAC.

Article VI Officers

Section 1 Elected Officers

The elected officers of the FAC shall be a Chairperson, a Vice-Chairperson, a Secretary, a Friends of HCH Liaison, and a HCH Family Resource Center Liaison.

Section 2 Duties

A. Chairperson — The duties of the Chairperson shall be those assigned by the FAC, including:

- be chief executive officer of the FAC
- prepare meeting agendas
- call and preside over FAC meetings
- be an ex-officio member of all committees
- provide overall direction of FAC activities
- be official spokesperson for the FAC

- keep members abreast of pertinent information affecting the FAC
- direct preparation of reports of the FAC as appropriate for distribution to RIH/HCH administration or appropriate individuals or groups

B. Vice Chairperson — The duties of the Vice-Chairperson shall be those assigned by the FAC or the Chairperson, including performance of the duties of the Chairperson under the following:

- assist as requested by the Chairperson
- in absence of the Chairperson
- when the Chairperson is unable to act
- in addition, the Vice Chairperson will maintain attendance and membership records
- and recruit new members

C. Secretary — The Secretary shall have recording and correspondence duties including the following:

- shall record minutes of all meetings which shall be given to each member at least seven (7) days before the next meeting
- shall maintain all correspondence

D. Friends of HCH — The Friends of HCH Liaison shall be a liaison between the Auxiliary and/or related entities of the FAC.

E. HCH Resource Center Liaison — The HCH Resource Center Liaison shall be a liaison between the HCH Resource Center and the FAC.

F. Immediate Past Chairperson — The immediate Past Chairperson shall serve as an ex-officio member for one (1) year.

Section 3 Nominations and Election

Nominations and elections shall be held in accordance with Article V, Section 3 of these by-laws.

Section 4 Term of Office

The elected officers shall assume their duties upon election at the Annual Meeting. Officers shall serve for a term of one (1) year or until their successors are elected and qualified.

Section 5 Vacancy of Office

Notification of a vacancy of office and intent to vote to fill said vacancy shall be included in the notice of the meeting in which the vote is scheduled. The vote can be acted upon at any meeting.

Section 6 Removal of Officers

Removal of officers shall be done in accordance with Article V, Section 7 of these by-laws.

Article VII FAC Committees

Section 1 FAC Standing Committees

FAC Standing Committees may be designated from time to time by amendment to these by-laws. The Chairperson shall appoint the Committee Members and Committee Chairperson, with approval of the FAC Board. The Standing Committee shall be:

A. HCH Design Committee — The Design Committee shall continue to address design issues regarding HCH.

B. HCH Resource Center Committee — The Resource Center Committee shall address issues regarding the HCH Resource Center.

C. HCH Patient Committee — The Patient Committee shall address issues regarding patient care.

Section 2 Special Committees

From time to time, special committees and their chairpersons may be appointed by the Chairperson of the FAC with approval of the FAC Board.

Section 3 Qualifications for a FAC Committee Chairperson

Each FAC Committee Chairperson shall be a member of the FAC Board.

Article VIII FAC Executive Committee

Section 1 Composition

The members of the FAC Executive Committee shall be the officers of the HCH FAC and the Immediate Past Chairperson, ex-officio, non-voting member. Other ex-officio, non-voting members may be added from time to time.

The FAC Chairperson shall preside at meetings of the FAC Executive Committee. In the absence of the Chairperson, the Vice Chairperson shall preside. The FAC Secretary shall act as Secretary of the FAC Executive Committee.

Section 2 Duties

During the intervals between the meetings of the FAC Board, the FAC Executive Committee shall act for and in place of the FAC Board. All action by the FAC Executive Committee shall be reported to the FAC Board for ratification at

its meeting next succeeding such action. The FAC Board may rescind or alter such action, however, no rights of third parties shall be affected by any such rescission or alteration.

Section 3 Meetings

Meetings of the Executive Committee shall be at the call of the FAC Chairperson.

Article IX Guidelines and Authority

The FAC has authority given it by the Administration, Medical Staff, and Board of Trustees of Hasbro Children's Hospital. It cannot enter into agreements or bind HCH in any other fashion. Events organized by the FAC on behalf of HCH are done so with prior approval of HCH Administration, Medical Staff, and Rhode Island Hospital Board of Trustees.

Article X Confidentiality

To maintain appropriate and confidential handling of personal information, HCH patient and/or family members shall not be discussed by name in FAC meetings.

Article XI Parliamentary Authority

The rules contained in the current edition of Robert's Rules of Order Newly Revised shall govern the proceedings of HCH FAC in all cases in which they are applicable and in which they are not inconsistent with these by-laws and any special rules of order that HCH FAC may adopt.

Article XII Amendment of By-laws

These By-laws may be amended by submitting the amendment in writing to the secretary, signed by at least three (3) FAC members. The secretary shall mail the proposed amendment ten (10) days prior to the regular FAC meeting at which said amendment shall be voted upon. Adoption of the proposed amendment shall require a two thirds (2/3) vote of the FAC Board.

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